SOCIAL SKILL DEVELOPMENT IN TEENAGERS WITH AUTISM WHO ARE HOMESCHOOLED IN RURAL SOUTHWEST: A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCE OF CAREGIVERS

by

Sondra J. Bistline

Liberty University

A Dissertation Presented in Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy: Education: Special Education

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APPROVED BY:

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Abstract

The purpose of this hermeneutic phenomenological study was to describe the caregiver's lived experience of social skill development in their teenage or young adult students who have autism. Vygotsky's social constructivism theory frames the structure of social development within the student's family, community, and local culture. The central research question guiding this study was, *what were the caregivers' lived experiences of social interactions with their homeschooled teenager or young adult diagnosed with autism?* All participants were caregivers of teenage or young adult students diagnosed with autism who received all or part of their schooling through homeschooling, micro-schooling, or habilitation services in their home in the rural Southwest United States. Data was collected in person and via electronic means (e.g., video conferencing) through journal writing, individual interviews, and focus groups. Journals, individual interviews, and focus groups were analyzed to triangulate the data to improve the reliability and validity of the data collected. Themes within the caregiver's lived experience were compared with themes that emerged across each caregiver's lived experience to identify effective practices for developing social skills among teenage and young adult students with autism. Themes developed from the data were caregiver resources and challenges, intervention services and planning for the future, and social maturation. By keeping their true natural environment constant during their formative years, teenagers and young adults may have better success at learning functional communication and self-regulation skills, which are foundational to learning social skills. Social skills, in turn, are foundational to successful integration into communities and workplaces and may help alleviate comorbidities of depression and mental illnesses.

Keywords: autism, social skill development, rural, homeschool, micro-school, social constructivism, natural environment, transition

Dedication

I dedicate this dissertation to God for sustaining me each day, to my late grandmother, who let me know that I could do hard things, and to my husband for picking up my slack and being a stalwart companion throughout every part of this journey. To my children and grandchildren – *you* can do hard things.

Acknowledgments

Dr. Park was my committee member during the first year of my dissertation. She helped me discover the focus of my research. Thank you for listening. Dr. Deck became my committee chair after the first year and helped me bring this project to fruition. Thank you for being concise and supporting my project as my project. Both professors were instrumental in this project.

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List of Abbreviations

Applied Behavior Analysis (ABA)
Activities of Daily Living (ADL)
American Psychological Association (APA)
Americans with Disabilities Act (ADA)
Applied Behavior Analysis (ABA)
Autism Spectrum Disorder (ASD)
Assistive Technology (AT)
Centers for Disease Control and Prevention (CDC)
Childhood Autism Rating Scale (CARS)
Cognitive-Behavioral Therapy (CBT)
Developmental Delay (DD)
Diagnostic and Statistical Manual of Mental Disorders, 1st ed. (DSM-I)
Diagnostic and Statistical Manual of Mental Disorders, 2nd ed. (DSM-II)
Diagnostic and Statistical Manual of Mental Disorders, 3rd ed. (DSM-III)
Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (DSM-IV)
Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (DSM-V)
Early Intervention (EI)
Evidence-Based Practice (EBP)
Free and Appropriate Public Education (FAPE)
Functional Communication Training (FCT)
Home and Community-Based Services (HCBS)
Individualized Education Plan (IEP)

Individuals with Disabilities Education Act (IDEA)

Intellectual Disability (ID)

International Statistical Classification of Diseases and Related Health Problems, 10th ed. (ICD-10)

Least Restrictive Environment (LRE)

The National Clearinghouse on Autism Evidence and Practice (NCAEP)

The National Professional Development Center on Autism Spectrum Disorder (NPDC)

National Standards Project (NSP)

Nonverbal Behaviors (NB)

Not otherwise specified (NOS)

Occupational Therapist (OT)

Peer-mediated Instruction and Intervention (PMII)

Pervasive Developmental Disability (PDD)

Pervasive Developmental Disability – Not Otherwise Specified (PDD-NOS)

Physical Therapist (PT)

Positive Behavior Support (PBS)

Quality of Life (QoL)

Self-Stimulating Behaviors (STIM)

Sensory Integration (SI)

Sensory Processing Disorder (SPD)

Specific, Measurable, Achievable, Relevant, and Time-bound (SMART) goal

Speech Generating Device (SGD)

Speech-Language Pathologist (SLP)

Speech Therapy (ST)

Theory of Mind (TOM)

Transcranial Direct Current Stimulation (tDCS)

Typically Developing Peers (TDP)

Workforce Innovation and Opportunity Act (WIOA)

Working Memory (WM)

CHAPTER ONE: INTRODUCTION

Overview

The guarantee of free and appropriate education for every student in the United States of America sounds fair and equitable; however, the execution of such a lofty goal falls short when students and their families live too far away from urban and suburban populations to access the resources and expertise available to some, but not all, students. The rural Southwest region of the United States, with large tracts of federally managed land, contains pockets of small towns and communities that are effectively isolated from more populated regions of their state. Hundreds of miles often separate these people from the closest major hospital, private or specialized school option, or university. The distance from potential service locations can be physically and financially prohibitive for adequate medical and educational interventions. This hermeneutic phenomenological dissertation will examine caregivers' lived experiences of social skill development in their teenage students who have autism. After reviewing the historical, social, and theoretical background of people with autism and the evolution of the diagnosis of autism spectrum disorder (ASD), the problem of poor social skill development emerged from limited school choice and appropriate professional intervention options. The significance of this study illustrates that the development of social skills impacts individuals, their families, their communities, and the broader world as children with autism become adults with autism. This chapter introduces the topic of the study, which highlights the influence of social skill development from the perspective of caregivers of those diagnosed with autism who live in rural areas in the Southwest United States. The chapter also introduces the central research question and three sub-questions for this study, followed by definitions of key terms and abbreviations.

Background

The autism spectrum disorder (ASD) of today has a storied past, spanning over a century and across developed countries around the globe. Through examination of the most relevant literature, the historical (e.g., how the problem has evolved), social (e.g., how society, community, education systems, and the economy are affected by the problem), and theoretical background of autism, the diagnostic evolution has changed from describing behaviors or symptoms displayed by affected children to blaming the parents, then back to describing behaviors. Some historical documents have been authoritative in medical, educational, and child development literature only to be countered or superseded by period documents that have become available through discovery, access, and translation (Manouilenko & Bejerot, 2015; Moskowitz & Heim, 2011; Sher & Gibson, 2021; Simmonds & Sukhareva, 2018; Ssucharewa & Wolff, 1996).

Historical Context

Characteristics of ASD began to be documented in Switzerland when Swiss psychiatrist Eugen Bleuler first taught about autism by describing the fundamental symptomatology of schizophrenia as inclusive of association, affect, ambivalence, and autism in his 1911 publication of *Dementia Praecox oder Gruppe der Schizophrenien* (Moskowitz & Heim, 2011). Autism was initially believed to be a mental disorder. Until the third edition of *The Diagnostic and Statistical Manual* was published in 1980, it was called schizoid psychopathy and referenced as various forms of schizophrenia, including childhood schizophrenia, or infantile psychosis (Harris, 2016). The *Diagnostic and Statistical Manual-3* classified the syndrome as Pervasive Developmental Disorder (PDD) to distinguish it from childhood-onset schizophrenia (Harris, 2016).

The earliest known publication of clinical descriptions of autistic traits was in 1926 by a largely forgotten Soviet child psychiatrist, Grunya Efimovna Sukhareva (Manouilenko & Bejerot, 2015; Sher & Gibson, 2021; Ssucharewa & Wolff, 1996). Her first clinical description of symptomatology in case studies of six boys was published in 1926 (Manouilenko & Bejerot, 2015; Simmonds & Sukhareva, 2020; Ssucharewa & Wolff, 1996). The second clinical description, published in 1927, was comprised of case studies of five girls and included notations about differences present in the group of girls as compared to the group of boys. The biological insufficiency of the syndrome included three components, which are now considered the triad of autistic characteristics: psychomotor impairment, emotional impairment, and differences in associative work and thinking (Simmonds & Sukhareva, 2020). Impaired emotional cognition was thought to be secondary to adverse life circumstances. Symptoms that Sukhareva identified as presenting differently between the group of girls and the group of boys included females having more difficulty regulating their emotions, yet the girls exhibited fewer peculiar interests than boys exhibited. Sukhareva also noted the importance of hyper-sensory or hypo-sensory abnormalities, which only recently appeared in the description of ASD in the fifth edition of *The Diagnostic and Statistical Manual* (DSM-V; Manouilenko & Bejerot, 2015; Posar & Visconti, 2017; Sher & Gibson, 2021; Simmonds & Sukhareva, 2020). Much of what has been discovered since the literature of the 1940s and combined in the DSM-V had already been published by Sukhareva, as the clinical descriptions of the biological insufficiency of the syndrome were included in articles that were published in 1926 and 1927 in Russian and German journals (Harris, 2016; Manouilenko & Bejerot, 2015; Sher & Gibson, 2021).

Many of the commonly credited contributors of descriptions about what would come to be known as ASD began publishing literature over a decade after Sukhareva (Fellowes, 2015;

Lyons & Fitzgerald, 2007; Muratori et al., 2021). Names of researchers who have historically been included in childhood development literature include Hans Asperger in Austria and the United States, J. Louise Despert in France and the United States, Leo Kanner in Austria and the United States, George Frankl in Austria and the United States, and Anni Weiss in Austria (Fellowes, 2015; Lyons & Fitzgerald, 2007; Muratori et al., 2021). The fact that Asperger, Kanner, Weiss, and Frankl all originated in Austria may serve to bridge the chasm that has been thought to be a strange coincidence given that each published similar descriptions around the same timeframe following Frankl's move from Austria to the United States during World War II, as it is now known that he had contact with both Asperger and Kanner in Austria (Lyons & Fitzgerald, 2007; Muratori, et al., 2021; Robison, 2017; Sher & Gibson, 2021; Vicedo & Ilerbaig, 2021). Admittedly, controversy has arisen around the work of Kanner because he was known to neglect to cite his sources and references (Blacher & Christensen, 2011; Fellowes, 2015; Kanner, 1949; Lyons & Fitzgerald, 2007; Manouilenko & Bejerot, 2015). After World War II, Bleuler's *Dementia Praecox oder Gruppe der Schizophrenien* was translated into English and introduced the term *autism* to the field of psychiatry, although decades would pass before the term came to be used to describe the spectrum of symptoms identified as ASD (Asperger, 1944; Harris, 2016; Moskowitz & Heim, 2011; Simmonds & Sukhareva, 2020).

In 1994, the fourth edition of *The Diagnostic and Statistical Manual* was published, linking genetic syndromes that presented with similar symptoms to PDD with the modifier "not otherwise specified" (PDD-NOS) to the consternation of many families and caregivers (Flores-Rodríguez et al., 2022; Harris, 2016). The DSM-IV and the *International Classification of Diseases, Tenth Revision* (ICD-10) expanded symptomatic criteria to include Asperger's syndrome and Rhett syndrome, later combined into ASD in DSM-V (Harris, 2016). Although

DSM-V combined multiple diagnoses and linked over 20 genetic syndromes to a single diagnosis, it also introduced specifiers to differentiate presentation types, including syndromic autism, idiopathic and syndromic autism, and social or pragmatic communication disorder, to ease frustration for families and intervention providers (Flores-Rodríguez et al., 2022; Harris, 2016; McKeithan & Sabornie, 2020). In DSM-V, ASD collapsed Asperger's, Rhett syndrome, and other genetic syndromes that presented with autistic-like symptoms, which were previously categorized as PDD-NOS, into the single diagnosis *autism* (Blacher & Christensen, 2011; Harris, 2016). Combining diagnoses into a single category allowed more children to qualify for services, which had previously been reserved for only those who had a diagnosis of autism; however, this diagnostic simplification had the unfortunate effect of parents and professionals over-generalizing minimal expectations to more children who presented with less severe symptoms (Blacher & Christensen, 2011; McKeithan & Sabornie, 2020).

Social Context

The prevalence of ASD has been increasing at a rapid rate, which has been having an impact on families, schools, and communities. While peer-mediated and peer-social networks have been continuously and actively used within inclusive and clinical settings, more than 60% of children with ASD who qualify for special education within the public school system were only partially included (Odom et al., 2021). Of this 60% of children, less than 80% of their time at school was in an inclusive setting, and many spent most of their school day in a self-contained special education classroom. While a student with a disability may need specialized academic instruction outside of the general classroom, socialization within self-contained special education classrooms was not representative of the child's natural environment, and social skills learned within the classroom may not generalize outside of that classroom (Crank et al., 2021; Kauffman et al., 2019; Sandbank et al., 2020).

Adequate social skill development will determine the adults' social acceptance and functionality within activities of daily living and when interacting with others in their community (Anderson et al., 2021; Solomon, 2020). When students enter secondary education, postsecondary education, and employment, these emerging adults with ASD must be knowledgeable about, ask for, and obtain support and accommodations for themselves (Anderson et al., 2021; Odom et al., 2021; Solomon, 2020). Students who have not developed sufficient social communication or self-determination skills by the time they have transitioned to adult roles are at a severe disadvantage (Odom et al., 2021; Solomon, 2020). Persistent disadvantages may be a barrier between adults with autism and the services or accommodations available in their communities (Solomon, 2020). Adequate social skill development determines adults' social acceptance and functionality within activities of daily living and when interacting with others in their communities (Anderson et al., 2021; Solomon, 2020).

Community involvement, including gainful employment, was necessary to facilitate integration into the community as full participants; however, less than half of young adults with ASD maintain even part-time employment (Solomon, 2020; Wehman et al., 2020). When compared to same-age adults with other learning or developmental disabilities, young adults with ASD (ages 18 to 25) have been less likely to have ever had a paying job and more likely to have disruptions, such as job loss or expulsion from higher education facilities (Anderson et al., 2021; Wehman et al., 2020).

As of 2001, ASD became a qualifying disability to receive funds from SSI (Anderson et al., 2020; Social Security Administration, 2022). Prior to the publication of DSM-V in 2013 and

International Statistical Classification of Diseases and Related Health Problems, 10th edition in 2015, the designation of autism was reserved for the most severely impaired, while other diagnoses that asserted a less widely held stigma, such as Asperger's syndrome, PDD-NOS, and other lesser-known diagnoses were marginalized due to less apparent symptoms (Anderson et al., 2020; Harris, 2016). With the increased diagnosis rate and diagnostic criteria changes, 326.8% more individuals with a diagnosis of ASD qualified for SSI benefits from the Social Security Administration between 2005 and 2015 (Anderson et al., 2020). Qualifying for SSI payments requires that recipients have a qualifying disability, earn less than $1,130 per month while employed, and have less than $2,000 in assets, not including a home, automobile, or other non-disclosed resources. Benefits decrease for individuals who work and earn more than $1,130 per month.

Due to the sudden ubiquitous presence of autism, the prognosis of an ASD diagnosis may be misunderstood by caregivers, educators, employers, and intervention service providers (Anderson et al., 2021; Chua et al., 2022; Grove, et al., 2021; McKeithan & Sabornie, 2020; Solomon, 2020). The combining of diagnoses with DSM-V was reportedly to extend intervention services to more children who presented with autistic-like behaviors. However, the effort may have had the additional effect of decreasing the expectations of what each child could ultimately achieve and what adults with ASD could contribute as members of their community (Anderson et al., 2021; Chua et al., 2022; McKeithan & Sabornie, 2020; Solomon, 2020). Parents, caregivers, or individuals receiving SSI benefits in lieu of employment may have diminished the motivation for persons with ASD to contribute as productive community members (Chua et al., 2022).

At over 50% unemployment, young adults with ASD may pose a strain on their families and society (Baker et al., 2020; Rogge & Janssen, 2019; Ruble et al., 2019; Wehman et al., 2020). When considering the billions of dollars spent in public and private school education from ages 2 through 21, publicly-funded programs, such as home and community-based services, state-funded health insurance, and the continued payment of SSI benefits, "it is not unreasonable to ask what we are doing, or perhaps not doing in the specialized education of students with ASD that leads to an absence of competitive employment" (Wehman et al., 2020, p. 1893). Documented unemployment rates for young adults with ASD in rural geographic locations were not found.

Research showed that the population of dependents with ASD ages 1 to 24 years have a 33% higher rate of asthma than the general population and experience a 277% increase in psychiatric comorbidities than their peers, which may account for adults with ASD who have had an increased comorbidity rate for anxiety, mood, psychotic, trauma, stress-related disorders, substance use disorder, and suicide attempts (Brooks et al., 2021; Dell'Osso et al., 2018a; Dell-Osso, 2018b; Kalb et al., 2016). Pervasive comorbidities may negatively impact the reliability of adults with ASD in the workplace (Anderson et al., 2021; Gadow et al., 2017; Wehman et al., 2020). Since ASD is not considered a curable condition, addressing the social aspect of the disability in a way that increases an individual's ability to interact with other people may allow each to reach their full potential by increasing employability while decreasing the likelihood of developing additional comorbidities, such as substance abuse, adverse behaviors, and mental illnesses (Anderson et al., 2020; Anderson et al., 2021; Dell-Osso et al., 2018; Sam et al., 2020; Sam et al., 2021; Solomon, 2020; Zweers et al., 2021).

The people who were closely connected to the lives of individuals with ASD have been vital to their overall development. For example, “despite complex realities, research shows that connections of home, school, and community remain important for student success in middle and high schools” (Epstein, 2011, p. 195). A homeschool or micro-school educational environment may offer students increased interactions with more knowledgeable others (MKOs), whether one-on-one with adults or through collaborative learning experiences alongside students with increased abilities, as they develop adaptive behaviors and social skills in preparation for integration into their communities (Dell’Armo & Tassé, 2019; Gaylord-Ross et al., 1984; Suppo & Floyd, 2012).

Because ASD is a disorder that includes a spectrum of symptoms and severity, it is impractical to assume the abilities or outcomes for each person who receives the diagnosis. While there are circumstances of greatest severity that would preclude active employment or engagement within the community, such as cases that would have most likely qualified squarely within previous descriptions of autism, caution must be exercised so that individuals with mild or moderate presentation of symptoms and severity are not excluded from active community engagement due to misconceptions based on previous diagnostic criteria or discomfort when interacting with persons with ASD due to poorly developed social skills.

Theoretical Context

In the 1930s, theorists who worked primarily in child psychiatry most closely associated some descriptions of schizophrenia with intelligent, distant parents who were cold in their interactions with their children, leading to the use of the destructive term *refrigerator mother* in the late 1960s, which still impacts attitudes and opinions today (Bettelheim, 1968; Blacher & Christensen, 2011; Despert, 1938, 1952, 1968; Evans, 2013; Fellowes, 2015; Kanner, 1943;

Sterwald et al., 2019). Theories associated with emotionally distant parents were used to frame treatment, which alternatively evolved and devolved. Treatment began as primarily institution-based, adult-led, and adult-reinforced peer interactions that included prompting, direct teaching techniques, and positive reinforcement, along with mixed results from applied behavioral analysis given the use of aversive procedures (Allen et al., 1964; Kirby & Toler, 1970; Lovaas, 1971; Lovaas, 1987). In the 1970s, social interventionist research began to focus on reciprocal social interactions instead of individual social behaviors, active involvement of parents in their children's learning and development, incorporation of peer-mediated reciprocal social interactions, and recognition that challenging behaviors could be a form of communication (Gaylord-Ross et al., 1984; Iwata et al., 1994; Odom & Strain, 1986; Schopler & Reichler, 1971; Strain & Shores, 1977; Strain et al., 1978). When aversive behavior management techniques were proven harmful in 1988, the psychiatric community was divided, but by 1997, the United States federal government issued the Individuals with Disabilities Education Act that, for the first time, mandated functional behavior assessments before developing a behavior plan and required consideration of positive behavior interventions to support students (Berkman & Meyer, 1988; Odom et al., 2021; U.S. Department of Education, 2022).

The interventions that began to be implemented in the 1970s were primarily informed and supported by the social constructivist theory as a collaborator or more knowledgeable other (MKO) took the form of a child's parent or peer during reciprocal social interactions (Epstein, 2011; Mooney, 2013; Odom & Strain, 1986; Vygotsky, 1978). Parents and peers were ideal MKOs because they shared values, beliefs, language, and problem-solving skills with which the child was most familiar (Odom & Strain, 1986; Strain & Shores, 1977; Strain et al., 1978; Vygotsky, 1978). The shared values, beliefs, language, and problem-solving skills would be familiar to children with ASD and provide a framework to learn socially appropriate behaviors within their own cultural experiences as they progress within their Zone of Proximal Development (Vygotsky, 1978). Given appropriate training and coaching by professionals, parents, and peers could be in an ideal position to support and reinforce, through scaffolding, the daily development of knowledge, skills, and abilities (Mooney, 2013; Odom & Strain, 1986; Strain & Shores, 1977; Strain et al., 1978; Vygotsky, 1978).

Problem Statement

The problem was that when school choice and intervention treatment services were limited or lacking due to geographical location, caregivers of students who lived in remote rural locations and who had a diagnosis of autism were at a severe disadvantage, as compared to their peers who lived in more populated areas where intervention services were more accessible (Barnard-Brak et al., 2021; DeAngelis & Dills, 2019; Singh et al., 2019; Tanet et al., 2020; Trout et al., 2020; Zhang et al., 2017). Educational needs that varied from mainstream services effectively separated students who had ASD from the social and educational environments of the general population of students, contributing to deficits in social skill development (Barnard-Brak et al., 2021; DeAngelis & Dills, 2019). Access to quality intervention services through local public schools or state agencies varied across rural and urban locales (Barnard-Brak et al., 2021; Mello et al., 2016; Suppo & Floyd, 2012; Zhang & Esghi, 2019; Zhang et al., 2017).

After a child was diagnosed with ASD, interventions to facilitate academic, physical, communicative, and social skill development depended on the availability of qualified and skilled intervention professionals (Barnard-Brak et al., 2021; Mello et al., 2016; Singh et al., 2019; Zhang et al., 2017). The availability of qualified and skilled intervention professionals who addressed communication and social skill development, usually Speech-Language Pathologists, was likely accessible when students were enrolled in local public schools but may not have been used if students were homeschooled or attended local micro-schools, particularly in rural areas. A micro-school could be made up of students from one or more families, could be held in a family's home or in a separate space, could have an interactive or online curriculum, and may or may not be funded by state monies (Bedrick & Ladner, 2020; Koteskey, 2018; Pandemic Pods, 2020; Tichy, 2021). Supporting services may be limited by location regardless of school placement. The development of social skills in teenage students who had an ASD diagnosis was indicative of how they live, work, and interact in their communities when they become adults (Bowring et al., 2019; Burke et al., 2019; Constable et al., 2018; Grossman & Mangaña, 2016; Hirano et al., 2018a; Hirano et al., 2018b; Rogge & Janssen, 2019; Welsch et al., 2019).

Social skill development in teenage students with autism who live in rural locations around the United States of America is underrepresented in the research literature. Families seeking alternatives to address educational, medical, and behavioral concerns may turn to homeschooling or micro-schooling (Simmons & Campbell, 2018; Zweers et al., 2021). This dissertation examined the caregivers' lived experiences as they sought to address social skill development for their students diagnosed with ASD.

Purpose Statement

The purpose of this hermeneutic phenomenological study was to describe caregivers' lived experience of social skill development for teenage and young adult students with autism in the rural Southwest. For the purpose of this research, social skill development was generally defined as socially appropriate interpersonal and intrapersonal interactions with familiar and unfamiliar conversational partners. The theory that guided this study was Vygotsky's social constructivism.

Significance of the Study

Social skills were essential to adults functioning in their communities, such as at work, in personal relationships, in online forums, and even when successfully performing daily living activities (Bowring et al., 2019; Butzbach et al., 2021; Ruble et al., 2019). Caregivers of teenagers diagnosed with autism were impacted by factors imposed by caring for the teenager who was developing into an adult. Adult caregivers, for the purpose of this study, regularly engaged in a teaching or mentoring capacity with the teenage or young adult student for 10 or more hours per week, in the role of parent, homeschool teacher or guide, habilitation, extended family member, or foster family member. Family members included grandparents or adult siblings. This section discusses this study's theoretical, empirical, and practical perspectives to illustrate the significance of the caregiver perspective on social skill development in teenage students diagnosed with autism.

Theoretical Significance

The practical hypothesis of appropriate social skill development was that a person with appropriate social skills will completely integrate into the community where they live and live a fulfilling life, which included meaningful personal relationships. Effective and practical social skills are acquired individually through interactions with MKOs in natural environments using a scaffolded approach (Vygotksy, 1978). Vygotsky's social constructivism advocates for the individual learning from the masses, or more knowledgeable others, rather than the masses learning from an individual. Social skill development occurred alongside cognitive development when students were motivated to interact with others, and social skill development was affected by shared values, beliefs, language, and problem-solving skills within the culture in which the person lived (Mooney, 2013; Vygotsky, 1978).

While school environments have been considered natural during childhood, public school abruptly ceased to be a natural environment upon transition when a student left school or reached the age of 22 and was no longer eligible to attend. Transitioning out of a public-school setting necessitated adequate social skill development for interpersonal interactions and self-advocacy, which was required to continue to receive services during adulthood (Movahedazarhouligh, 2021; O'Brien et al., 2019; Odom et al., 2021; Welsh et al., 2019). Transitioning from home to involvement in the broader community as an adult also required adequate social skill development for self-advocacy and interpersonal interactions. By examining caregivers' lived experiences regarding their students' social skill development, I describe how the experiences have affected interpersonal interactions at home and within the community. This study's findings may contribute to advancing social skill development practices by caregivers, as MKOs, for teenage students with autism in related circumstances.

Empirical Significance

This study may add contextual variables to the literature published about social skill development in people who have autism. Research showed that although empirically based treatments for autism are effective, treatments have not markedly improved the patients' lived experiences, suggesting the need for more research on why and how interventions ought to be implemented to facilitate the development and generalization of social skills into real-world interactions throughout the development of individuals who have autism (Callahan et al., 2008; Odom et al., 2021; Paynter et al., 2018; Trembath et al., 2018). Social skills, such as problem-solving, perspective-taking, prediction, and even purposeful deception, were skills best learned in a child's natural environment; children with autism learned new things best when environmental factors were consistent before introducing variability in factors, such as location and communication partners (Crank et al., 2021; Sandbank et al., 2020; Welsh et al., 2019). Problem-solving skills were necessary to provide a foundation for higher cognitive functions, which included non-verbal skills for social interactions (Constable et al., 2018; Welsh et al., 2019). Children who were diagnosed with ASD have difficulty with problem-solving, social communication, and interactions in various environments, which often resulted in a communication mismatch with people around them (Espelage et al., 2015). This mismatch may be due to environmental inconsistency (Welsh et al., 2019). By examining the lived experiences of caregivers who educate their teenage students with ASD at home or within a micro-school context, I hoped to add to the literature by illustrating how social skills may develop within environments outside of public schools, especially for students who live in rural areas.

Practical Significance

As the prevalence rate of autism was above 2.2% of children age 8 and 2.5% of the overall school population in the United States, bridging the communication and social skills gap for children with autism so they can enter adulthood as more fully participating members of their communities had become an essential area of focus (Anbar, 2022; Centers for Disease Control and Prevention, 2022; Hirano et al., 2018a; Hirano et al., 2018b; Iovannone & Anderson, 2022; Ruble et al., 2019; Schott et al., 2021). Parent training and continued intervention within the home and community were not well-represented in the literature, particularly regarding teens with ASD and the development of their social skills in preparation to transition into adult roles, including planning, setting goals, implementing strategies, and accessing adult disability services (Hirano et al., 2018a; Hirano et al., 2018b; Ruble et al., 2019; Schott et al., 2021; Singh et al., 2019; Suppo & Floyd, 2012). Accessibility of transition services and adult disability services in rural locations was also noticeably absent from the literature (Schott et al., 2021; Singh et al., 2019). Adults with ASD and their families who lived in rural areas had limited access to services, including transportation, medical and behavioral services, parent training services, individual or family support groups, and independent living options, which effectively isolated individuals from connecting to vital services and opportunities for further education, employment, and social relationships with peers (Odom et al., 2021; Schott et al., 2021; Singh et al., 2019; Suppo & Floyd, 2012). When these services were neither offered during the transition from a public school nor readily available within the community, obtaining access to services became the responsibility of the person with ASD (Odom et al., 2021; Singh et al., 2019). An individual adult's social skill development when self-advocating for services or seeking help from others in their community impacted their receiving of those services (Odom et al., 2021; Singh et al., 2019). Results from this study likely informed parent participants of teenage and young adult students who were homeschooled or attended micro schools about transition and the availability of services in their area better, brought more attention to the plight of underserved populations who have developmental disabilities and lived in rural locations around the United States, and may possibly generalize to affect change in both educational option availability and the availability of the home, community, and behavioral service (HCBS) provision policy.

Research Questions

Social constructivism theory posited that children learn from MKOs in their natural environments (Vygotsky, 1978). MKOs may be parents, teachers, community members, or more advanced peers. By examining the lived experiences of caregivers, I sought to derive common practices that facilitated or hindered the development of social skills and novel approaches that have produced positive results. The research for investigating the experiences of adult MKOs was guided by one guiding research question and three sub-questions.

Central Research Question

What were the caregivers' lived experiences of social interactions with their homeschooled teenagers and young adults diagnosed with autism?

Sub-Question One

How did caregivers describe their students' social interactions with family members?

Sub-Question Two

How did caregivers describe their students' social interactions in community settings?

Sub-Question Three

As a more knowledgeable other (MKO) in their student's life, how did the caregiver ensure their student reached an appropriate zone of proximal development (ZPD) to live as independently as possible?

Definitions

1. *ASD* – Autism spectrum disorder is a neurodevelopmental disorder characterized by deficits in social communication, social interactions, and restricted or repetitive patterns of behavior, interest, and activities. Symptoms of ASD vary in presentation across affected individuals (American Psychiatric Association, 2022).
2. *HCBS* – Home and community-based services allow Medicaid beneficiaries to receive services in their home or community rather than in institutions or other isolated settings (Medicaid.gov, 2022).

3. *MKOs* – More knowledgeable others are adults, teachers, and more capable peers who collaborate by assisting the child in recognizing what they already understand and reinforce that understanding (Vygotsky, 1978).

Summary

The problem was that when school choice and intervention treatment services were limited or lacking due to geographical location, students who lived in remote rural locations and who had a diagnosis of autism were at a severe disadvantage when compared to their peers who lived in more populated areas where intervention services were more accessible (Barnard-Brak et al., 2021; DeAngelis & Dilla, 2019; Singh et al., 2019; Tanet et al., 2020; Trout et al., 2020; Zhang et al., 2017). Teenage students' social skill development indicated how they would live, work, and interact in their communities when they were adults. This hermeneutic phenomenological study aimed to interpret caregivers’ lived experiences of social skill development in their teenage and young adult students with autism and sought insights into what families did to provide effective and practical social interventions for their students. Effective social interventions prepared students to advocate for themselves in their workplaces and postsecondary educational settings. Adults with ASD must know which accommodations and support services are available, their needs, and how to communicate them. Adequate social skill development determined adults' social acceptance and functionality within the workplace, in higher education institutions, when engaging in daily living activities, and when interacting with others in their homes and communities. For the physical, mental, financial, and emotional health of adults with autism, social skill development was essential. This study sought to contribute additional and unique insights to the existing literature advocating for the successful transition of teens with ASD to adults with ASD through the development of functional social skills.

CHAPTER TWO: LITERATURE REVIEW

Overview

A systematic review of the literature for this proposed study explored the problem of social skill development and the role of individualized education for teenage and young adult children, ages 12 to 30, who had autism spectrum disorder (ASD) and lived in the rural United States. This chapter reviewed the current literature related to the topic of study, including the role of caregivers. The first section will discuss the theory of social constructivism and is followed by a synthesis of recent literature regarding the development of social skills in children with autism. Finally, literature published about the efficacy of public schools, homeschools, and micro-schools in developing social skills in children with autism is addressed. Several gaps were identified in the literature. Three primary gaps included the need to address the devaluation of people with autism who lack sufficient social skills to engage in their communities in a meaningful way, an underrepresentation of people who live in rural communities who lack adequate access to support resources, and false assumptions regarding access to services that were often more available to those who lived in urban and suburban communities than those available for individuals and families living in rural settings.

Theoretical Framework

Regardless of diagnosis, teenagers begin the process of differentiation from their caregivers and authority figures through intentional acts so they can be recognized as distinct individuals while exploring their sense of self (van Manen, 2016). An emerging adult often seeks to be recognized as a different and separate being from their adult caregivers while simultaneously learning appropriate social skills to engage in adult activities and responsibilities. Social skills are necessary to facilitate positive interpersonal interactions within those adult activities and responsibilities. and the development of appropriate social skills typically occurs alongside cognitive development when students are motivated to interact with others during this process (Mooney, 2013; Vygotsky, 1978).

Theory of Social Constructivism

Vygotsky's (1978) theory of social constructivism centered on shared values, beliefs, language, and problem-solving skills within a culture and the perpetuation of that culture across generations. According to the theory, "learning and development are interrelated from the child's very first day of life" (Vygotsky, 1978, p. 84). The social experiences within family, educational, and community settings instilled and reinforced values, beliefs, language, and problem-solving skills (Epstein, 2011; Vygotsky, 1978). The corresponding cultural influences were introduced and reinforced through experiences throughout the child's development. Continuation of the culture depends on the culture's ability to perpetuate a set of values, beliefs, language, and problem-solving skills across generations. Perpetuation necessitated meaningful interactions between more knowledgeable others (MKOs), such as parents, extended family members, neighbors, teachers, mentors, and more capable peers, and the child within social contexts to provide experiences that ultimately fostered the child's growth and assimilation into the culture.

Lev Vygotsky introduced the Zone of Proximal Development (ZPD) to describe the distance between the actual developmental level, as demonstrated through problem-solving, and the level of potential development, given guidance by MKOs (Mooney, 2013; Vygotsky, 1978). The ZPD identified emerging knowledge, skills, and abilities that have yet to mature and asserted that social and cognitive development build upon each other. The Zone of Proximal Development was the only specific construct that Vygotsky's work outlined; however, his work has spawned additional theoretical constructs that have been enthusiastically embraced by many of those who have studied child development during the past decades.

Constructs that evolved from Vygotsky’s original work include the idea of MKOs and the concept of scaffolding, both of which continue to be referenced throughout educational and psychological literature. The first evolutionary construct, MKOs, was defined as adults, teachers, or more capable peers who collaborate with a child to assist them in recognizing the truth that was familiar and then reinforcing that truth by employing common sense (Vygotsky, 1978). The second construct, scaffolding, refers to the guidance provided by MKOs to increase successful performance, understanding, and skill level. Vygotsky (1978) believed that “the mere exposure of students to new materials through oral lectures neither allows for adult guidance nor for collaboration with peers” (p. 131). His work emphasized the family, community, values and beliefs, education, and culture shaping a child’s social experiences and nurturing social skill development (Epstein, 2011; Mooney, 2013; Vygotsky, 1978). Vygotsky’s work was drawn from German psychologist K. Koffka and other theorists, such as Karl Marx and F. Engles, psycho-neurologist K. N. Kornilov, and psychologist G. I. Chelpanov (Britannica.com, 2022; McLeod, 2018). Chelpanov’s theories were left incomplete, and because his original work was written in Russian and continues to be translated decades after his death, seminal work is not directly available (McLeod, 2018).

The theory of social constructivism provided a framework to describe the social development of teenage students with autism who were homeschooled or attended local micro-schools as they transitioned from childhood to adulthood. The theory was relevant primarily because of the diverse maturational variability across individuals diagnosed with ASD. After obtaining lived experiences from caregivers of these students, I have described how the student’s social skills have developed within the context of homeschooling or attending a micro-school, described social language interventions that have been used, and described social interactions within both educational and community settings in rural locations in the Southwest United States. There was limited related literature regarding social development for young adults who had autism and lived in rural communities, regardless of the method by which they received educational and developmental services. The findings of this study may contribute to the advancement of social skill development practices for teenage students with autism across all settings because there was a gap for this population in the literature, including how caregivers of these students, as MKOs, perceived their role in helping develop necessary social skills to facilitate the successful transition into their communities and into adult roles where the student would be required to advocate for themselves.

Related Literature

A literature review suggested that interventions learned in natural environments were most effective and had a higher likelihood of generalization for students who had autism (Crank et al., 2021; Movahedazarhouligh, 2021; O'Brien et al., 2019; Welsh et al., 2019). For children with ASD, social skills may need to be learned in the specific locations and contexts where they will be used. Location, time, and the audience may need to be specific to learn these skills and facilitate accuracy in practice, which may lead to future generalization of those skills (Bauminger-Zviely et al., 2019; Callahan et al., 2008; Callahan et al., 2017; Crank et al., 2021; Puckett et al., 2017).

Social Skills in ASD

Social skills impairment was the core problem facing children with autism and their caregivers, yet social skills services remained the highest unmet need (American Psychiatric Association, 2013; Flores-Rodriguez et al., 2022; Kasari & Patterson, 2012; Scarpa et al., 2020;

Schott et al., 2021; Turcotte et al., 2016). Autism is a spectrum disorder, meaning that symptoms can present very differently from one person to the next; ASD affects social interactions due to limited communication, restricted and repetitive movements and interests, and socially disruptive behaviors (Lai et al., 2014, Lee et al., 2020; Rispoli et al., 2019b; Sam et al., 2020; Sam et al., 2021). Early intervention was cited as the most effective way to improve communication, social, and behavioral skills (Gevarter et al., 2022; Irwin et al., 2002; Lai et al., 2014; Marks, 2017; McCormick et al., 2019; Movahedazarhouligh, 2021; O'Brien et al., 2019; Wergeland et al., 2022). However, even with early intervention, a child's communication, social interaction, and behaviors would likely change dramatically as they entered adolescence and adulthood, which could present another opportunity for growth around social skills and interpersonal interactions with various age populations in their communities rather than primarily peers who were in a contained environment (McKeithan & Sabornie, 2020; Wergeland et al., 2022; Zaharia et al., 2021; Zweers et al., 2021).

Communication skills precede social and behavioral skill development, as it is necessary to communicate a person's wants and needs to reduce anxiety and aggression, which can lead to poor social interactions and unacceptable behaviors (Anderson et al., 2021; Kasari & Patterson, 2012; Lai et al., 2014; McKeithan & Sabornie, 2020; Olkin et al., 2019; Paul, 2007; Wergeland et al., 2022). Once a method of communication was established at a functional level, self-management skills were developed through the cultivation of problem-solving skills and positive emotion regulation strategies. Following the development of self-management skills, improved higher cognitive functions often emerged as the child became more motivated to better understand non-verbal cues and nuances that were exhibited by others during social interactions

(Aljadeff-Abergel et al., 2015; Constable et al., 2018; McKeithan & Sabornie, 2020; Trembath et al., 2018; Zaharia et al., 2021).

People who had autism were reported to receive more benefit from a purposefully scaffolded approach to social interactions than typically developing children, and students with ASD often required repeated experiences in natural environments in order to learn and practice for the generalization of specific social skills, such as participation in activities with different people and variability of context (Aljadeff-Abergel et al., 2015; Anderson et al., 2021; Crank et al., 2021; Dudley-Marling, 2004; Edwards-Jones et al., 2018; Kesler et al., 2016; Knight et al., 2013; Solomon, 2020; Vygotsky, 1978). If a child could engage flexible thinking about the application of social skills in a new or different way, generalization would likely be more straightforward (Crank et al., 2021; Dudley-Marling, 2004). Successful experiences accompanied by positive feedback during practice sessions may naturally lead to increased motivation and volition, which has the potential to carry learning about positive social behavior into adolescence and adulthood (Aljadeff-Abergel et al., 2015; Anderson et al., 2021; Constable et al., 2018; Keller, 2008; Kesler et al., 2016; Kvande et al., 2019; Ledbetter-Cho et al., 2018; Levy & Perry, 2011; Marston, 2019; Wehman et al., 2020).

Theory and Practice

Although there were some exceptions, students with autism do not typically seek out social interactions in person or through social media (Simpson et al., 2017). Instead, they may be voracious consumers of unidirectional media, such as movies, television shows, and playing video games; persons with ASD often exhibited problematic behaviors and abnormal attachment when using video games (Aguillon-Hernandez et al., 2020; Simpson et al., 2017). Interventions that built on a child’s interest by introducing social or academic activities to increase understanding would be an example of MKOs using scaffolding within the ZPD (Escolano-Perez et al., 2019; Lee et al., 2020; Mooney, 2013; Vygotsky, 1978). According to the theory of social constructivism, an ideal practice would involve parents, caregivers, teachers, and administrators who worked together with a child to ease transitions between school years, schools, or school levels, such as elementary, middle, high school, and postsecondary settings. The adults who worked together could regularly communicate about events or circumstances which might influence the behaviors or participation of a child and work to increase the child's sense of belonging and likelihood of experiencing success during transitions (Epstein, 2011; Lee et al., 2020; Ruble et al., 2019). However, there are some impediments that may create obstacles that stand between ideal practices and what is currently practiced.

A 2020 study conducted in every inclusive public elementary school in Kuwait revealed an "urgent need to provide training in IEP processes of development, implementation, and evaluation for all special education teachers" (Al-Shammari & Hornby, 2020, p.179). Pre-service and in-service teacher training for all teachers, including special education teachers, was essential for developing meaningful and attainable goals on Individualized Education Plans (IEPs), appropriately implementing plans, regularly evaluating student progress through consistent data collection to determine the efficacy of the interventions, and providing opportunities to make adjustments when needed (Al-Shammari & Hornby, 2020; Iovannone & Anderson, 2022; King et al., 2018; Swain et al., 2021). According to Sam et al. (2020) "knowing which practices are effective and are supported by research is not enough to lead to increased use of such practices" (p. 1931). Proper implementation of evidence-based practices (EBP) required training and conceptual buy-in from educational stakeholders, especially for new teachers and paraeducators with little training in working with students who have ASD (Iovannone &

Anderson, 2022; King et al., 2018; Sam et al., 2022). Improper or insufficient training, limited teacher support, and lack of resources were cited as contributing factors to high rates of teacher turnover in the field of special education; turnover may contribute to higher rates of school refusal among students and fewer successful transitions when students are no longer eligible to attend public school (Bitsika et al., 2021; Conley & You, 2017; Hirano et al., 2018; McKeithan & Sabornie, 2020; Schott et al., 2021; Swain et al., 2021; Turcotte et al., 2016).

Early Intervention Services

Early intervention (EI) services were offered to children who were referred to and identified as having or being at risk of developing a developmental delay or learning disability. The diagnosis of autism may occur as early as 18 months of age, but it was usually diagnosed between 38 and 120 months of age (Centers for Disease Control and Prevention [CDC], 2022). Babies and toddlers who demonstrated developmental delays, and who might later be diagnosed with autism, were eligible to receive services to address the delays. Families and caregivers might not be aware of appropriate developmental milestones, or they might have believed that a child would grow out of symptoms of autism. While some children might catch up without intervention, others fall further behind developmentally when they did not receive specific support (Barnard-Brak et al., 2021; Irwin et al., 2002; Rossetti et al., 2020). In some instances, developmental delays were not recognized, and the child was not referred for EI services. In those cases, the children with delays might not be identified at an age where they could benefit from early EI services because home-based services ended when a child turns 3, and those services transitioned to school-based interventions through local school districts (CDC, 2019). School-based services are widely available in all states, but when service providers are not readily available in rural communities, families are often not offered the choice to participate

(Barnard-Brak et al., 2021; Janus et al., 2019; Rossetti et al., 2020; Scarpa et al., 2020; Zhang et al., 2017). Young children who had delayed communication and social skill development were at an increased risk for problem behaviors, such as increased aggression, withdrawal, low compliance, and poor social skills (Gray et al., 2008; Irwin et al., 2002; Janus et al., 2019; Zhang et al., 2017). A delay in service delivery could postpone the initiation of interventions indefinitely, depending on the severity of symptom presentation and a family's eventual awareness of resource availability (Gadow et al., 2017; Rossetti et al., 2020).

A family-centered approach to providing early intervention in a child's natural environment was essential because the family was a constant in a child's life, and interventions could be incorporated into frequently occurring daily routines (Movahedazarhouligh, 2021; O'Brien et al., 2019; Wergeland et al., 2022; Witwer et al., 2022). Family members were best suited to support the development of their children when they had the resources and support that they needed (O'Brien et al., 2019; Wergeland et al., 2022; Witwer et al., 2022). In-home support services were ideal as they enhanced caregivers' competency and strengthened the family. To avoid disrupting family activities and routines, intervention efforts were embedded into daily activities and routines, which then became a regular and natural part of those routines (O'Brien et al., 2019; Simmons et al., 2022; Wergeland et al., 2022; Witwer et al., 2022).

Incorporating interventions into routines helped to generalize skills quicker than if the activities were done only during therapy sessions. Every family was unique, so individualized intervention strategies were necessary to address their circumstances and requirements (Kikas et al., 2016; Miller et al., 2017; Simmons et al., 2022; Wergeland et al., 2022). Early identification of delays, disorders, and disabilities, which had the benefit of in-home service provision, could help the entire family begin the process of special education, preparing students to transition into the public school system for the continuation of services at the age of 3 (Barnard-Brak et al., 2021; Gray et al., 2008; Wergeland et al., 2022).

The philosophy of family-centered care promoted the child's treatment within the family context to optimize a child’s developmental outcome (Gray et al., 2008; Witwer et al., 2022; Wergeland et al., 2022). Treatment goals and planning were conducted in collaboration with the caregivers to assist the family in managing the child’s needs and increase recognition of student effort and achievement (Flores-Rodriguez et al., 2022; Iverson et al., 2003; Miller et al., 2017; Witwer et al., 2022; Wergeland et al., 2022). Emphasizing the role of family members in the development of children with ASD was often imperative for the desired positive impact of intervention services.

Transition to the Public School System

The benefits of early intervention in the home are well-documented. However, as children age, intervention services were provided more often within the context of the public school system rather than in the natural environments for the children (Janus et al., 2019). Changes to service location necessitated that teachers be familiar with the supports and services provided by early intervention services so that they could continue to provide resources and supports to families (O’Brien et al., 2019). Caregivers who had the knowledge and skills they needed to support the development of their children with autism, or any other developmental delay, could become a teacher’s ally, since families are typically the best resource for information about children (Grossman & Magaña, 2016; Janus et al., 2019; Miller et al., 2017; O’Brien et al., 2019). However, due to disagreements about a child’s placement, the child’s aversive behaviors, territorial covetousness, or beliefs held by poorly trained staff, caregivers could be seen as adversaries of teachers and may begin to question the efficacy of the public school system for their child (Esposito et al., 2019; Simmons & Campbell, 2018). An adversarial relationship could become exacerbated by a child's behavior due to poor communication and social skill development when they are young, which could present as bullying, victimization, fighting, student-teacher conflict, and low peer acceptance (O'Brien et al., 2019).

Individualized Intervention

While academic and social interventions existed, autism necessitated individualization for those interventions to be successful (Barbieru, 2016; Kikas et al., 2016; Saint-Georges et al., 2020; Tanet et al., 2020; Trussell et al., 2018). Whether limited opportunities for adequate education were due to diminished resources, inadequate training, or a worldwide pandemic that demanded social distance, the persistent academic and social needs of children with autism remained (Green-Hennessey & Mariotti, 2021; Neuman & Oz, 2021). Research showed that children with autism benefitted from being with their peers in a school setting, yet there was a disparity between what was published in the research literature and common educational practices (Bitsika et al., 2021; Smogorzewska et al., 2020; Tanet et al., 2020; Trussell et al., 2018). In addition, a frequent occurrence in both general education and special education was a decrease in caregiver involvement as children moved into higher grades, affecting an ever-widening chasm of roles and perspectives between caregivers at home and school personnel (Hirano et al., 2018a; Hirano et al., 2018b; Kurth et al., 2019; Rossetti et al., 2020; Scanlon et al., 2018).

Inclusion: ASD In the Classroom

Public schools in the United States could refuse entry to a school-aged child for any reason, which was not true in other countries. For example, in China, "many [French] children with severe ASD and ID initially cannot be placed in mainstream or even special education classrooms, especially if significant behavioral problems are present" (Tanet et al., 2020, p. 13) (Baker et al., 2020; Tanet et al., 2020). In some nations around the world, alternative schools might be made available; however, if a school was not local to the family's residence, it could require that the family relocate to the proximity of the school, or it might remove the child from the family home environment to be placed in a boarding school arrangement (Baker et al., 2020; Gauthier-Boudreault et al., 2017; Tanet et al., 2020). The same was not true in the United States, which highlighted the need for all public-school settings to recognize their role in meeting the needs of the local community.

In the United States, a genuine challenge occurs when a child with autism was placed in a mainstream or special education classroom where their behaviors disrupted other class members because the student with ASD did not have adequate social skills (Bitsika et al., 2021). Without adequate social skills to communicate wants and needs or to refrain from unwelcome outbursts or behaviors, social rejection could undermine students' educational experience, thus increasing occurrences of school refusal (Bitsika et al., 2021; Trussell et al., 2018).

People who worked in special education usually joined the profession because they had compassionate hearts and wanted to help, but those who left special education usually left because they felt overworked and under-appreciated (Conley & You, 2017; Swain et al., 2021). There seemed to be a strain so severe that those compassionate hearts were worn out within a few years. Leaving special education was not an option for many students who had a more severe presentation of ASD, even when they were frustrated about changing teachers, aides, programs, procedures, furniture arrangements, and routines (Bitsika et al., 2021; Trussell et al., 2018). Feelings of frustration were often manifested as behavioral problems and could easily result in negative experiences and school refusal (Bitsika et al., 2021; Trussell et al., 2018;

Zweers et al., 2021). Negative social and school experiences with teachers and peers during late elementary and middle school years contributed to low self-esteem and poor psychosocial adjustment in school and later life (Bitsika et al., 2021; Zweers et al., 2021). Despite the willingness of special educators, stressful situations and events could limit the academic and personal success of students with ASD.

Home-School Collaboration

Collaboration between a child's home and the various teachers and intervention providers in public schools to create a family-school partnership could improve the long-term generalization of skills learned by the student (Rispoli et al., 2019b). Unfortunately, cooperation was not the norm, as caregivers might not have fully understood the IEP process or the professional language used in IEP meetings and felt excluded from meaningful collaboration (Rossetti et al., 2020; Trainor, 2010). Caregiver stressors could be negatively affected by factors, such as low social support, poor relationships with extended family members, limited educational achievement, lower income, the child's age, the length of time since the diagnosis, and the child's problem behaviors (Mire et al., 2021). The child's problem behaviors might significantly contribute to a caregiver's level of stress (. Perceived unrealistic expectations of medical and educational professionals might exacerbate these stressors. Through meaningful collaboration with medical and educational professionals to address caregivers' concerns, feelings of stress could be reduced and engender feelings of empowerment (King et al., 2018; Rispoli et al., 2019b). Reducing the perceived stress of caregivers was essential because "higher parenting stress predicted elevated levels of child problem behaviors, and parenting stress could affect caregivers' ability to attend to their children's needs, including participating in their child's treatment" (Mire et al., 2021, p. 661).

Caregiver Training

Caregiver involvement through attendance at IEP meetings was a predictor of post-school employment and attendance at postsecondary education institutions (Hirano et al., 2018a; Hirano et al., 2018b). If public education aimed to produce independent, contributing adults, then parent involvement was invaluable in achieving that purpose (Hirano et al., 2018a; Bishop et al., 2000; Walton, 2021). Parent involvement was also critical for a student to obtain employment (Ruble et al., 2019). Caregiver involvement was critical to students' successful transitions from secondary school settings to postsecondary education, employment, independent living, and dependent living; caregivers had to be knowledgeable and confident in their role as advocates for long-term life goals (Gauthier-Boudreault et al., 2017; Goldman & Burke, 2019). How caregivers learned to advocate depended on their experiences, accessibility to information, and sense of empowerment (Burke et al., 2018; Burke et al., 2019; Gauthier-Baudreault et al., 2017; Suppo & Floyd, 2012). Families with an advocate who helped guide and support them through intervention services, including the special education process, demonstrated significantly greater knowledge about ASD and reported experiencing less stress (Burke et al., 2019). Partnering with an advocate suggested that the benefits could go beyond navigating the disability and special education processes by having a positive impact of relieving the stress expressed by caregivers.

Academic Interventions that Positively Impact Social Skills

Building academic and social resilience resulted in better student outcomes academically and in social interactions (Elias, 2021; Knight et al., 2013; Smogorzewska et al., 2020; Zweers et al., 2021). The emergence of academic achievement and successful social interactions in the lives of children with ASD was slower than observed in their typically developing peers (Flores-Rodriguez et al., 2022; Grove et al., 2021). The delay in academic and social skill development could negatively impact children's interpersonal and intrapersonal relationships, which could result in stigmas and social isolation (Bitsika et al., 2021). Negative social relationships with teachers and peers put students at risk for developing psychological and academic problems, while executive function deficits related to planning, sequencing, and problem-solving generated the most difficulty regarding academics and daily living activities (Bonete et al., 2022; Elias, 2021; Escolano-Perez et al., 2019; Zweers et al., 2021). Conversely, developing emotional resilience resulted in positive social motivation toward academic and social perseverance (Dell'Armo & Tassé, 2019; Elias & White, 2020; Kvande et al., 2019; McCormick et al., 2019; Rispoli et al., 2019b).

Early childhood experiences that addressed planning, sequencing, and problem-solving, as Maria Montessori advocated, were an excellent place to begin if options and information were available to families when a child was young (Barbieru, 2016; Flores-Rodriguez et al., 2022; Marks, 2017; Mooney, 2013; Singh et al., 2019). For families who lived in areas where such options were not available or not widely known, it was imperative to inform medical providers, public school personnel, public officials, and even local librarians who could disseminate information so that those community stakeholders could pass along accurate information to families when the need arose (Flores-Rodriguez et al., 2022; Rossetti et al., 2020; Singh et al., 2019; Zhang et al., 2017).

Social Interventions

Insufficient interpersonal socialization skills was the most prevalent problem cited by people who had autism (American Psychological Association, 2022; Flores-Rodriguez et al., 2022; Kasari & Patterson, 2012). According to Autism Speaks (2022), "social skills are the rules, customs, and abilities that guide our interactions with others and the world around us" (https://www.autismspeaks.org/social-skills-and-autism). Regardless of location, the integration of students with different abilities and disabilities has been shown to have a positive effect on the development of the theory of mind, or an awareness of the emotional and mental states of other people, particularly when given purposeful direction of attention and activities by a MKO (McCormick et al., 2019; Smogorzewka et al., 2020). Social interventions were often implemented within schools, with minimal generalization to settings outside those schools (Callahan et al., 2008; Callahan et al., 2017; Carruthers et al., 2020). While school settings were widely considered to be natural environments, they did not reflect the environments or social interactions the child would encounter outside of a school and minimized the generalization of those social skills from school to home or from home to school (Carruthers et al., 2020; Trembath et al., 2018; Welsh et al., 2018).

Children who were diagnosed with ASD had difficulty with problem-solving, as well as social communication and interactions across all environments. The difficulties often resulted in a communication mismatch with people around them (Espelage et al., 2015). Communication mismatches could be due to environmental inconsistency (Welsh et al., 2019). Social skills, such as problem-solving, perspective-taking, prediction, and even purposeful deception, were best learned in a child’s natural environment since research showed that children with autism learn new things best when environmental factors are consistent (Welsh et al., 2019). Problem-solving skills were necessary to provide a foundation for higher cognitive functions, which included non-verbal skills for social interactions (Constable et al., 2018; Welsh et al., 2019). Research showed that middle-school-aged children with autism could learn specific behaviors and strategies which allowed them to participate in social interactions by successfully managing their behaviors and receiving social validation from people who were important in their lives (Callahan et al., 2017; Espelage et al., 2015; Simmons et al., 2022; Trembath, 2018).

The use of EBP could have a positive impact when developing social skills. The EBP report outlined practices that had been identified by The National Clearinghouse on Autism Evidence and Practice and National Standards Project in 2020 (*The National Clearinghouse on Autism Evidence & Practice*, 2020). Specific, measurable, achievable, relevant, and time-bound goals included one or more EBPs, which were embedded in therapeutic interventions to meet specific outcomes that, for students aged 14 to 22, triangulate postsecondary goals, state content standards, and the realities of life after transition where employment skills, trade skills, and independent living skills were needed (Kurth et al., 2021; Peterson et al., 2013; Shogren et al., 2021). For example, embedded EBPs like self-management, response interruption and redirection, and cognitive behavioral instructional strategies could be used as underlying EBPs within positive emotion regulation strategies that were reported to increase mindfulness, decrease anxiety, depression, and aggression common in people with ASD, which would make a person easier to live with and with whom to communicate (Frolli et al., 2021; Maddox et al., 2017; Rispoli et al., 2019; Zaharia et al., 2021).

Self-management skills and emotion regulation strategies were shown to result in improved adaptation, improved emotional control, and decreased emotional distress, allowing space for the development of social skills (Hume et al., 2021; Mazefsky et al., 2014; Rispoli et al., 2019; Simmons et al., 2022). Emotion regulation for preschool-aged children with autism might be successfully implemented using a parent-mediated approach (Rispoli et al., 2019). Other EBPs, like Antecedent-Based Interventions, may look like a first-then style cueing system, while reinforcement might incorporate a reward or praise whenever the target behavior was used.

EBPs were not specific programs; they were proven components of interventions that could be incorporated into formal or informal programs.

Emerging interventions included Augmentative and Alternative Communication, Exercise and Movement, Functional Communication Training, Music-Mediated Interventions, and Technology-aided Instruction and Intervention. There was evidence that social skills groups, peer-mediated interventions, and technology-based interventions were effective for some students with autism (Bertilsdotter-Rosqvist, 2019; Brady et al., 2020). Studies that added to the body of literature to support these practices were listed in Appendix R, along with intervention programs that were available.

Transition to Society

Children with developmental disabilities grow up to be adults with developmental disabilities. Research showed that low self-esteem, poor communication, poor attention skills, and poor psychosocial adjustment could hurt a child-turned-adult's higher education options, getting and keeping a job, finding and keeping friends, or even living independently of parents or family members; positive behavioral support often lead to improvement in a person's quality of life (Bowring et al., 2019; Fuentes et al., 2021; Grossman & Magaña, 2016; Schott et al., 2021; Zweers et al., 2021). When a person with autism transitioned as an adult into society, typically at 22 years old, they were no longer eligible to attend public school. It was expected that they would be full participants in conversations, business transactions, independently obtain services they needed, and follow the social norms of the community (Bowring et al., 2019; Schott et al., 2021; Trainor et al., 2016; Turcotte et al., 2016).

Community-based behavioral health support interventions were shown to decrease the frequency of hospitalization, emergency room visits, and the number of medications prescribed to adults who had intellectual or developmental disabilities (Owen et al., 2017; Singh et al., 2019). Additionally, transition support services could result in decreased monetary costs to society and improve self-management through collaborative efforts between families, communities, and the transitioning adult (Callahan et al., 2017; Grossman & Magaña, 2016; Owen et al., 2017; Puckett et al., 2017; Rogge & Janssen, 2019; Schott et al., 2021; Singh et al., 2019; Turcotte et al., 2016). If a child lived in an area where Positive Behavior Support Teams were actively employed, and their family and support members knew about and actively participated with the teams, a child-turned-adult could benefit by having a scaffolded entry out of the public school system and into their community (Bowring et al., 2019; Grossman & Magaña, 2016; Hirano et al., 2018a; Hirano et al., 2018b; Rogge & Janssen, 2019). If these services were unavailable in the family's community, families were left to create support within their communities or to do without support (Schott et al., 2021; Singh et al., 2019).

Community Resources

Autism, like other developmental delay diagnoses, involved educational and medical interventions (Autism Speaks, 2022; Doshi-Velez, 2014; Fuentes et al., 2021). Community healthcare service availability and specializations had an impact on the timeliness and level of services offered to children and their families (Barnard-Brak et al., 2021; Bowring et al., 2019; Doshi-Velez, 2014; Gray et al., 2008; Hand et al., 2021; Trout et al., 2020). Community resources and perspectives toward children transitioning from school and into the community influenced the success of transitions, and although transition planning was legally mandated for more than two decades, young adults with behavioral and social disabilities continued to experience poor postschool outcomes (Bowring et al., 2019; Fuentes et al., 2021; Grossman &

Magaña, 2016; Trainor et al., 2016). Poor transitioning could be due to the continuation of poor social skills (Fuentes et al., 2021; Simpson et al., 2017).

Caregiver Roles in Developing Social Skills

Whether a child would eventually live independently of their caregivers or be a lifelong dependent, it was in the interest of caregivers to ensure that a child with ASD developed the best possible social skills (Zaharia et al., 2021; Zweers et al., 2021). Caregivers of children with autism searched for treatments to help their children, often with inaccurate information, to alleviate their child's aversive behaviors (Aljadeff-Abergel et al., 2015; Leaf et al., 2021). Given improved information and knowledgeable service coordination, caregivers would be better equipped to sift through the multitudinous intervention schemes and information to find actual EBPs (Aljadeff-Abergel et al., 2015; Leaf et al., 2021; Witwer et al., 2022). Given the extensive marketing efforts of companies that promote books, programs, methods, and devices aimed at parents of children with autism, many families spent inordinate amounts of money hoping for a cure (Leaf et al., 2021; Paynter et al., 2020).

Current Practice of Caregiver Training

Although special education teachers, paraeducators, and specialists were essential, long-term caregiver involvement continued to be more important for the generalization and continuation of learned skills (Epstein, 2011; Rispoli et al., 2019b; Simpson et al., 2017). Just as early training followed by feedback was vital for teachers and paraeducators to generalize the use of EBPs, caregivers needed to receive training throughout their child's development, followed by regular and consistent feedback (Sam et al., 2022). By law, IEPs in the United States must include parent involvement, but parent involvement is interpreted differently by individual educators, administrators, and caregivers. Caregiver involvement can vary from caregivers being included in school interventions and sometimes unidirectional training of specific behavioral techniques to full family-school partnerships (Grossman & Magaña, 2016; Rispoli et al., 2019; Suppo & Floyd, 2012). Full family-school partnerships were typically defined, developed, and encouraged by fully informed and well-trained staff, since few caregivers understood the complex processes and nuances of special education services for a child with autism.

Homeschool and Micro-Schools

Homeschooling may look different each time it is implemented. Homeschooling could look like a miniature replication of a traditional school scenario of one adult leading or lecturing a group of seated children, or it could look like chaos, as children work in different areas on different projects while an adult watches over the different activities (Gaither, 2009; Martin-Chang et al., 2011; Neuman & Oz, 2021). Homeschooling might consist of a curriculum that the caregiver selects. Curriculum options included a pre-printed curriculum that was purchased by the caregiver, a fully online curriculum supplied by a third party or a homeschool shell, or a hybrid of printed and online content (Gaither, 2009; Green-Hennessy & Mariotti, 2021). However, the educational environment had only one or a few children present, was outside a traditional brick-and-mortar school building, and could be in the family's home (Gaither, 2009; Neuman & Oz, 2021). Depending on the state where homeschooling occurs, the requirements for adults varied from no restrictions or requirements for teaching credentials to full-teacher certification, and some states required regular home visits by state-appointed personnel along with mandates for students to take standardized tests. Homeschooling families were likely to measure academic achievement by skill level instead of yearly grade advancement, thereby granting credit for learning rather than time spent at a desk (Bishop et al., 2000; Gaither, 2009; Green-Hennessy & Mariotti, 2021; Neuman & Oz, 2021). Although the published number of homeschooled children may have only represented half of such students as of 2016, the reported number was approximately 3% of all schoolchildren in the United States (Green-Hennessy & Mariotti, 2021; Neuman & Oz, 2021).

Micro-schools hail back to the days of the one-room schoolhouse while simultaneously leaping forward through the incorporation of the technologies of today (Bedrick & Ladner, 2020; Geng et al., 2019; Horn, 2016; Koteskey, 2018; Tichey, 2021). Micro-schools were the free market's answer to perceived inadequate educational opportunities offered by public schools, and they "will rise or fall on [their] ability to meet customer needs at the right price" (Koteskey, 2018, p. 27). Critics cited inequality regarding the education received by micro-schooled students compared to students educated in public schools, with students attending micro-schools having the advantage; as families discovered alternatives to traditional public-school education, an ever-widening equity gap emerged and led to a loss of enrollment in public schools (Pandemic Pods, 2020). In response to parental concerns about the quality of their children's education, micro-schools offered a scaled back size with more individualized experiences (Bedrick & Ladner, 2020). Micro-schools differed from homeschooling in that they could have between six and 150 children, include students from kindergarten to twelfth grade, have certified teachers or employ parents as guides, meet in various locations, and encouraged each child to advance at their own pace through self-directed learning rather than maintain sameness with other children their age (Bedrick & Ladner, 2020; Geng et al., 2019; Horn, 2016; Koteskey, 2018; Neuman & Oz, 2021). Personalized goals assisted each child in discovering and fulfilling their own special calling in life as micro-schools remained student-centered (Koteskey, 2018; Tichey, 2021).

Why Families Chose to Homeschool or Micro-School

Since before the inception of the United States of America, the education of children has been held as a right and responsibility of parents (Walton, 2021). Education was expected to include reading in English, understanding the laws of an area, and the basic tenets of the Christian religion (Walton, 2021). Recognizing that religious beliefs varied across families, religion could be reasonably cited as a motivation for choosing to homeschool for educational delivery, but it is not just religion that keeps families at home (Gaither, 2009; Neuman & Oz, 2021). As of 2003, only 30% of parents indicated that religion and morality factors prompted them to homeschool their children (Gaither, 2009). Families from diverse cultural and linguistic backgrounds cited their choice to homeschool for various reasons, including preserving their first language and religious beliefs (Bower, 2019; Roseberry-McKibbin, 2021). In a 2020 article, reasons for homeschooling were historical inequality within the educational institution and families' desires to regain agency and self-determination (Dennison et al., 2020). Wearne (2019) reported three top reasons given by families for choosing to participate in a hybrid charter school that incorporated homeschooling with formal schooling: smaller class sizes (81.7%), better learning environment (74.9%), and more individual attention for their child (67.6%). Religion, preservation of cultural tradition, historical inequality, class size, the desire to provide better education to their children, and concerns about the public school environment were just a few reasons cited by researchers who sought to understand why families choose to homeschool (Bower, 2019; DeAngelis & Dills, 2019; Dennison et al., 2020; Gaither, 2009; Green-Hennessy & Mariotti, 2021; Roseberry-McKibbin, 2021; Wearne, 2019). Another reason for choosing to homeschool, particularly relevant to this study, was the availability of alternatives to the assigned public school (DeAngelis & Dills, 2019; Neuman & Oz, 2021). Why a family chose to homeschool varied widely from one family to the next. Regarding the availability of choice, homeschooling or micro-schools could be the only alternatives available to families who live in rural settings.

Caregivers of a child with autism might choose to homeschool because of complicated relationships between their child and teachers, other students, or staff members, along with bullying, which was shown to contribute to school refusal (Bitsika et al., 2021). Evidence showed that negative school experiences had a corresponding negative impact on academic and social development (Bower, 2019; Neuman & Oz, 2021; Simpson et al., 2017; Zweers et al., 2021). In addition to the motivating factors of caregivers of students who had ASD, family stress, child safety, dissatisfaction with educational placement, non-delivery of special education services, and interference with other pursuits, such as demanding sports, acting, modeling, travel, and other time-sensitive activities, were also cited as reasons for choosing to homeschool (Bower, 2019; Gaither, 2009; Neuman & Oz, 2021; Simmons & Campbell, 2018).

Another poignant factor for choosing to homeschool was the likelihood that the family members would remain the primary source of support and advocacy for a child or sibling who had ASD throughout their lifetime (Grossman & Magaña, 2016; Schott et al., 2021; Turcotte et al., 2016). Realizing that a person with autism might have minimal reserves for contextual learning, families might choose to capitalize on the most frequent and vital contexts as "ecological theory posits that there are multiple levels of influence on individuals and their outcomes and focuses on the interaction between the person and his/her environment," which would be in a person's home and regularly-attended locations in the community (Grossman & Magaña, 2016, pp. 239-240).

The decision of whether to homeschool was complex and ever-evolving. Factors that drove the decision to homeschool at one point may not be the same in the future. Families may choose to homeschool due to perceived safety issues, perceptions of the quality of education, or circumstances unique to a specific family (Bitsika et al., 2021; Green-Hennessy & Mariotti, 2021; Neuman & Oz, 2021). Research showed that families chose to homeschool at a mean grade of 4.33 based on long-standing or unresolved problems or a single catalyst event that prompted a change in educational delivery (Simmons & Campbell, 2018). Individualized interventions, which included peer support, instructional choice, and direct support during tasks that required scaffolding, could decrease instances when families refuse public-school options and reduce escape-maintained behaviors (Bitsika et al., 2021; Geng et al., 2019; Smogorzewska et al., 2020; Trussell et al., 2018).

Special Considerations for Those Who Chose to Homeschool

Although homeschooling could provide increased individualization of education for children with autism, few caregivers were prepared to implement academic and social interventions without skilled guidance from trained professionals; many caregivers were unaware of opportunities and school-based services that remained available to them and their children (Dennison et al., 2020; Simmons & Campbell, 2018). Academic and social skills were essential to a successful transition into the community while improving the likelihood of a fulfilling life (Dell'Armo & Tassé, 2019; Hirano et al., 2018b; McKeithan & Sabornie, 2020; Odom et al., 2021; Solomon, 2020). By examining the motivations of families in choosing to homeschool, educational professionals could better understand the needs of families and their children with autism regardless of the academic setting (Dennison et al., 2020; Hirano et al., 2018a; Hirano et al., 2018b; Odom et al., 2021; Solomon, 2020; Suppo & Floyd, 2012).

As every family is unique, individualized intervention strategies were necessary. Factors that impacted virtually every family in a study conducted in 2003 included time, support systems, education, communication, relationship, scheduling, follow-through, and caregiver roles (Edwards et al., 2003). Because caregivers knew their children best, it would seem natural for caregivers to act as advocates for their children; however, caregivers often did not understand the special education process, their rights within the law, or how their children's needs could be met (Burke et al., 2018; Burke et al., 2019; Dennison et al., 2020; Goldman & Burke, 2019; Lohmann et al., 2018; Ruble et al., 2019). Special education advocates could benefit families who homeschooled their children or chose public schools. Currently, special education advocates are not widely available; the same is true for advocacy training opportunities that should be easily accessible to educate caregivers (Burke et al., 2018; Burke et al., 2019; Trainor, 2010; Ruble et al., 2019; Suppo & Floyd, 2012). Because caregiver involvement improved short-term and long-term outcomes for children, building caregivers' competence and confidence was strongly positively correlated to a successful transition from school to postsecondary education, employment, and independent living (Hirano et al., 2018b; Lohmann et al., 2018; Ruble et al., 2019).

How Families Homeschool or Micro-School

Academic writers addressing parental homeschooling of children with ASD vary widely in their views of the adequacy of caregivers as teachers. Some were critical of parents, citing that the parents did not implement EBP or failed to meet the minimum standard requirements of time or content, while authors of other studies were complimentary of the parents and their homeschooling operation (Anthony & Burroughs, 2012; Bishop et al., 2000; Simmons & Campbell, 2018). Additional research described how parents identified appropriate instructional goals and then selected methods to meet them, including utilizing community resources and incorporating virtual or independent study materials (Anthony & Burroughs, 2012; Barbieru, 2016; Marks, 2017; Singh et al., 2019). As each caregiver or group of caregivers implemented differing practices, it was suggested that traditional schools could learn from the second homeschool model, as it utilized homeschool cooperatives, community colleges, online courses, video instruction, and individual study (Anthony & Burroughs, 2012). Not all homeschools were caregiver-driven. Some homeschools were available online with a full curriculum, certified assigned teachers, and daily or weekly accountability requirements; examples included various versions of [State] Virtual Academy K-12 programs. There were many iterations of micro-schools within the United States. Micro-schools could look like community education cooperatives, neighborhood homeschooling groups, specialized magnet-marries-Montessori-style schools, or commercial shells that provided a framework and curriculum; examples included Acton Academies, AltSchool, Khan Lab School, New Commonwealth Schools, Prenda® Micro-schools, Quantum Camp, and Wildflower Schools.

Rural Community Resources for Children with Autism. Children with autism in rural America had the same needs as children with ASD in urban America. Nevertheless, there were typically fewer resources and a diminished understanding of disability, given the material and self-perpetuating culture of poverty in many rural communities (Scarpa et al., 2020; Tierney, 2015). Brown and Swanson (2003) attested that “persistent stereotypes have diverted scholarly attention away from rural children and their healthy psychosocial development” (p. 97). The result was a large and diverse population of children who were overlooked (Barnard-Brak et al., 2021; Brown & Swanson, 2003; Scarpa et al., 2020; Suppo & Floyd, 2012; Tierney, 2015; Zhang et al., 2017; Zhang et al., 2019). Like their urban counterparts, rural communities in America often have religious institutions that might assist their church members in meeting the unmet physical and spiritual needs of families who cared for a child with a disability, but only to the extent that members were knowledgeable or skilled (Grossman & Magaña, 2016; Singh et al., 2019). Qualified instructors were less likely to live in rural communities than urban ones (Barnard-Brak et al., 2021; Scarpa et al., 2020; Singh et al., 2019). For example, "music therapy appears to be the most effective tool for improving social interaction in preschool-aged children with ASD" (Tanet et al., 2020, p. 2). However, music therapy and other programs specialized to address the needs of people with a diagnosis of autism were rarely available in rural communities (Barnard-Brak et al., 2021; Rossetti et al., 2020; Singh et al., 2019; Zhang et al., 2017). Medical providers in rural communities, including intervention specialists, were usually generalists and might be limited in their familiarity with specific disabilities, including ASD (Barnard-Brak et al., 2021; Scarpa et al., 2020). Online support networks have increased in recent years, providing information, insights, and social and emotional support to caregivers of those with autism and other health impairments who may not have had access to in-person support; however, users of such support groups are primarily extroverts, and the information obtained might not be entirely accurate (autismspeaks.org, 2022; Milios et al., 2022).

Urban Community Resources for Children with Autism. Communities where several families had children with common disabilities or adults who had similar disabilities could act as a support group for each other and disseminate information about resources and available services (Bertilsdotter Rosqvist, 2019; Grossman & Magaña, 2016; Milios et al., 2022; Nevill et al., 2018; Suppo & Floyd, 2012). Choice of charter, private, public, Montessori, or specialized schools had an increased availability in urban and suburban communities, while homeschools and micro-schools had an increased likelihood of availability in all locales (Tichy, 2021; Zweers et al., 2020). A wider variety of qualified instructors were more likely to live in urban communities (Barnard-Brak et al., 2021; Scarpa et al., 2020; Singh et al., 2019). Finally, medical providers in populated areas, including intervention specialists, were more likely to be specialized and provide a comprehensive network for referrals within a reasonable distance for families to travel (Barnard-Brak et al., 2021; Scarpa et al., 2020). The enhanced availability of supporting services in more populated communities helped highlight the disparity of options in rural locations, even though those same services were needed in various communities and settings.

Summary

Children with poor social skills grow up to be adults with poor social skills. Research showed that early intensive behavior interventions reduced social difficulties inherent in autism through positive emotion regulation strategies and social and cognitive interventions that addressed communication skills and problem-solving (Frolli et al., 2021; Herrero & Lorenzo, 2020; Irwin et al., 2002; Reichow et al., 2018; Rispoli et al., 2019; Trembath et al., 2018; Zaharia et al., 2021). Research showed that the education of children with disabilities could be made more effective by strengthening the role and responsibility of caregivers through caregiver consultation and training so that families could feel assured that their children had meaningful opportunities to participate in the community, followed by more successful transitions to meaningful employment, independent living, and postsecondary education (Callahan et al., 2017; Kauffman et al., 2017; King et al., 2018; Rispoli et al., 2019b; Scarpa et al., 2020; Trainor et al., 2016; Trembath et al., 2018). Caregiver participation positively affected behavior, language, communication, and social skills. Positive effects of caregiver participation on social skill development have been documented in young children and throughout the transition into adulthood, mainly when families were active participants in meaningful planning and the implementation of intervention services (Dell'Armo & Tassé, 2019; Grossman & Magaña, 2016; Nevill et al., 2018; Rispoli et al., 2019b; Suppo & Floyd, 2012).

Decreased home-to-school communication trends correlated with negative social and school experiences with teachers and peers during late elementary and middle school years were documented as contributing to low self-esteem and poor psychosocial adjustment in school and later life (Zweers et al., 2021). Poor home-to-school communication could manifest as poor transitioning into adult life, resulting in a lower standard of living through a decreased ability to get or keep a job, difficulty finding and keeping friends, increased emergency room and hospital visits, increased prescribing of medications, increased diagnosis of mental illnesses, and increased likelihood of living as dependents of parents, other family members, or in state-sponsored group homes (Anderson et al., 2021; Odom et al., 2021; Owen et al., 2017; Grossman & Magaña, 2016; Rogge & Janssen, 2019; Solomon, 2020; Wehman et al., 2020).

As the prevalence rate of ASD was over 2% of 8-year-old children and the projected annual cost to U.S. taxpayers will be $461,000,000,000 by 2025, it is imperative that society find a way to bridge the communication and social skills gap for children with autism so that they can enter adulthood as more-fully participating members of their communities (Anbar, 2022; CDC, March 2022; Rogge & Janssen, 2019). There was a gap in the literature regarding the effects of caregiver training and how teenage students who were diagnosed with autism continued to need intervention within their homes and from their families beyond the age of 3 alongside MKOs during collaborative learning experiences as they developed their social skills in their community, and during activities of daily living, as outlined in Vygotsky's theory of social constructivism (Vygotsky, 1978). There was also a gap in the literature regarding intervention services in rural America. The gap was indicative of a general cultural devaluation of adults with disabilities, particularly those who lived in rural locations. This study filled gaps in the literature by increasing awareness of the diagnostic over-generalization of limited abilities of those diagnosed with autism (McKeithan & Sabornie, 2020).

CHAPTER THREE: METHODS

Overview

This hermeneutic phenomenological study interpreted caregivers' lived experiences of social skill development in teenage and young adult students with autism spectrum disorder (ASD). Chapter three discusses why hermeneutic phenomenology was selected as the research design to study the lived experiences of caregivers. The research was guided by a central research question (CRQ) and three sub-questions (SQs). The setting and adult caregiver participants were described with Lev Vygotsky's theory of social constructivism as the interpretive framework (Vygotsky, 1978). The ontological, epistemological, and axiological assumptions that impact the researcher's philosophy were described, and the researcher's role as a human instrument, observer, interventionist, and interpreter was explained. The procedure section outlined necessary and appropriate permissions and the plan for recruiting adult participants for the study's population. Next, the data collection procedures are described, which consist of three approaches: journal writing, individual interviews, and a focus group. Details about how the data was synthesized after collection follows. Finally, trustworthiness measures describe the lengths taken to ensure this phenomenological study's quality and rigor were designed, as outlined by the methods employed by the framework; no information was collected from participants without necessary approvals.

Research Design

A qualitative research design was appropriate for this study because each homeschooled student and their family had different experiences. Each student's educational, familial, and life experience played a unique role and contained various contributing factors that impacted each student's social skill development (Moustakas, 1994; van Manen, 1997; van Manen, 2016). The contributing factors for the details of a person’s life cannot be fully identified or acknowledged without examining the lived experiences of the students who have a diagnosis of autism and who are educated at home or within micro-schools within their communities. Qualitative research allowed the researcher to elicit lived experiences, explore participants' perceptions, analyze those experiences and perceptions, and then identify themes that emerged during analysis (van Manen, 1997).

Phenomenology was pioneered by Edmund Husserl in the late 1800s and continued developing well into the 1900s (Beyer, 2020; Husserl & Lauer, 1965). His work was rescued after he died in Germany in 1938, initially taken to the Belgian archives by Franciscan Herman Leo Van Breda (Beyer, 2020; Husserl & Lauer, 1965). In the late 1900s, phenomenological research was subdivided by two researchers, Clark Moustakas, who championed transcendental phenomenology, and Max van Manen, who championed hermeneutic or interpretive phenomenology (Moustakas, 1994; van Manen, 1990; van Manen, 1997). While transcendental phenomenology requires that the researcher be separate and interpret only what is directly observed, hermeneutic phenomenology invites the researcher to fully engage in the research of the phenomenon both objectively and subjectively to obtain the most significant depth of understanding (Moustakas, 1994; van Manen, 2016).

Hermeneutic phenomenology was selected for this study because Hermeneutic phenomenology is used to examine the lived experience of human beings, inviting the researcher to explore the experiences and reach an appropriate level of depth of engagement when researching a phenomenon so that both objective and subjective observations help to provide a full and rich description (van Manen, 2016). Phenomenology offers the flexibility of studying a phenomenon by gathering qualitative data. Hermeneutics allows the researcher to interpret meaning from themes as they emerge through the lens of a practicing interventionist and to increase understanding about human behavior as phenomena occur within specific contexts. Due to the variability inherent in the study of caregiver perspectives, ASD, and social skill development, a flexible methodology was necessary.

Hermeneutic phenomenology is made up of essential steps. First, the researcher turns to the nature of lived experience by formulating a research question. Then, the researcher begins to investigate an experience as it is lived by conducting interviews or focus groups (van Manen, 2016). Third, after data is collected and interviews have been transcribed, the researcher reflects upon essential themes in a search for the overall meaning of the informants' experiences by writing and rewriting while visualizing the informants' feelings, thoughts, and attitudes. Throughout the writing process, the researcher strongly focused on the research question while balancing the context by considering its parts and the data as a whole. The qualitative research design selected for this study was the hermeneutic phenomenological design. The hermeneutic phenomenological design integrated the researcher's professional knowledge and skills in social skill development and intervention while interpreting the caregivers' lived experiences. Integrating intervention methods and social skill development was expected to improve the readers' ability to select and apply the most effective methods in their situation and context.

Research Questions

Social constructivism theory posits that children learn from more knowledgeable others in their natural environments (Vygotsky, 1978). More knowledgeable others may be parents, teachers, community members, or more capable peers (Vygotsky, 1978). By examining the lived experiences of caregivers, I expected to derive common practices that facilitated or hindered the development of social skills and novel approaches that produced positive results.

Central Research Question

What were the caregivers' lived experiences of social interactions with their homeschooled teenagers and young adults diagnosed with autism?

Sub-Question One

How did caregivers describe their students' social interactions with family members?

Sub-Question Two

How did caregivers describe their students' social interactions in community settings?

Sub-Question Three

As a more knowledgeable other (MKO) in their student's life, how did they ensure their student reached an appropriate zone of proximal development (ZPD) to ive as independently as possible?

Setting and Participants

This section describes the proposed setting and participants' demographics. The setting appropriate for this study, since participants and their students were not in a central location, was a rural region of the Southwest United States, isolated from much of the state's population by geological, socioeconomic, and cultural barriers. Participant selection of caregivers is described in this section, along with the anticipated demographics of the participants.

Setting

The setting for this study was in the rural Southwest of the United States, comprised of four communities that extend over 50 miles and have a combined population of 7,843 (United States Census Bureau, 2022). The distance to the nearest major hospital within the state was approximately 250 miles. The distance to the nearest university within the state was approximately 200 miles. Cultures within this range include descendants of early settlers from the 1800s, a Native American reservation, several polygamous sects, and various individuals who moved to the area more recently. Most services were obtained in the neighboring state with a few significant exceptions, including medical, educational, and therapy services funded by state programs. This setting was chosen for this project because of its isolation from the rest of the state, low adult education level, strong cultural influence across leadership within local schools, few licensed service providers, and a high rate of disabilities in the population of both adults and children (Leingang, 2019; Statista, 2019).

Participants

Participants in this study were caregivers of students diagnosed with autism who received all or part of their education through homeschooling, participation in a local micro-school, or continue to receive habilitation interventions as adults. Adult participants were regularly engaged in a teaching capacity with teenage and young adult students in the role of parent, homeschool teacher or guide, habilitation, extended family member, or foster family member. Family members included grandparents and adult siblings. Often, the engagement was in the context of homeschooling or a micro-school environment where a parent, guardian, or another caregiver spent 10 or more hours per week with the student. Adult participants were adults over 18 years of age and were not limited based on gender, ethnicity, or socioeconomic status. As most residents in the geographical region were white, participants were Caucasian, but the region was comprised of many diverse cultures, presenting cultural variability among the study's population. Socioeconomic status and parent education levels vary considerably within the region. One local satellite branch of a community college served the area, and the local dropout rates at the middle and high school levels were far higher than reported at the state level (United States Census Bureau, 2022).

Recruitment Plan

Initial participants were identified by known association with homeschooling and their relation to a child diagnosed with ASD. There was no formal homeschool organization in the region. The agencies that provided services to families in the area agreed to allow me to solicit the participation of adult caregivers with whom they work. Additional participants were identified by referral from other participants through snowball or chain sampling. I sought to include 12 to 15 adults, with saturation determining the maximum number of participants. Saturation was to be considered met when sufficient information had been gathered to depict the guiding theoretical framework, when new information stopped surfacing during interviews, and when interviewees began to refer the researcher to other key knowledge holders who had already been interviewed (Mthuli et al., 2021; Sebele-Mpofu, 2021). Due to changing demographics between the study's proposal and the data collection period, saturation was met at six participants under the initial criteria. After collected data was analyzed and the final paper was being written, the researcher was made aware of the university's policy of a minimum of 10 participants in each study. After discussion with committee chair, the researcher expanded the participant pool to include young adults who had been homeschooled or were continuing to receive habilitation interventions as adults. Data was collected with IRB approval and proper permissions and consents first being collected (Appendix A).

Researcher's Positionality

As the researcher, I identified meaning through the participants' lived experiences. Meaning arose as "the result of an interpretation of a past experience looked at from the present" (van Manen, 2016, p. 147). A researcher's values and beliefs are affected by their ontological, epistemological, and axiological assumptions, which inform how problem statements and research questions are formulated (Creswell & Poth, 2018). How the researcher formulates their problem statement and research questions subsequently influences how data is collected and how that data is interpreted in a hermeneutic phenomenological design (Creswell & Poth, 2018; van Manen, 1990; van Manen, 2016). This section presents the interpretive framework selected for this study, including my ontological, epistemological, and axiological assumptions as the researcher; it also describes my role as the researcher.

Interpretive Framework

Although the social context of Vygotsky's social constructivist theory mirrors many of my beliefs, I also believe that additional factors play an essential role in a person's overall development. Internal factors, such as a person's individual experiences not shared by the community and how those experiences are interpreted, will undoubtedly impact a person's values, beliefs, language, and problem-solving skills. External factors, such as travel or moving between communities, may also impact the development of an individual. Social experiences within family, educational, and community settings serve to reinforce values, beliefs, language, and problem-solving skills. However, when families, schools, and communities change through death, divorce, relocation, or other major life events, those experiences may alter a child's values, beliefs, language, and problem-solving abilities. The countless variations of experiences cannot be controlled. Therefore, I designed my research study within the social constructivism framework initially proposed by Lev Vygotsky. Social constructivism was the best fit for this research study because of the holistic nature of receptive social learning and expressive social interaction, particularly within family units (Schunk, 2020; Vygotsky, 1978). Because autism is currently understood as a diagnosis that can present at various points along a spectrum for each developmental segment of social interaction, communication, and imagination, the reality of any lived experience for an individual or family who lives with ASD may look different from any other individual's or family's lived experiences (Baynard-Brak et al., 2021; Florian, 2014; Mello et al., 2016; Singh et al., 2019; Trout et al., 2020; Zhang & Eshghi, 2019). The likelihood of multiple realities necessitated interpretation to discover the underlying meanings and how those meanings developed for each individual or family (van Manen, 1990). As a professional Speech-Language Pathologist who worked with children and adults with autism across medical and educational settings for over a decade, I was well-versed in social skill development across a person's lifespan.

Philosophical Assumptions

My philosophical assumptions were included to assist the reader in knowing more about my perspective and biases. Philosophical assumptions encompass a scholar's values and belief systems that are instilled through personal and professional experience, educational training, the documents that have been read, and the people with whom a person engages (Creswell & Poth, 2018; Lincoln & Guba, 1985). These assumptions may evolve but remain essentially unchanged throughout the scholar's life (Lincoln & Guba, 1985). The three philosophical assumptions are ontological, epistemological, and axiological.

Ontological Assumption

Ontological assumptions are beliefs about the nature of reality (Creswell & Poth, 2018). As a Christian, I believe that a loving God sent each human being and that each has value and purpose on this earth. Although the social context of Vygotsky's social constructivist theory mirrors many of my beliefs, I believe additional factors play an essential role in a person's overall development. Internal factors specific to an individual's experiences and how those experiences are interpreted may not be shared by others. They will likely impact personal values, beliefs, language, and problem-solving skills. External factors, such as traveling or moving from one community to another, will also impact an individual’s development. Experiences, such as family dynamics, educational background, and community characteristics, can help to reinforce values, beliefs, language, and problem-solving skills. However, when families, schools, and communities change through major life events, such as death, divorce, and relocation, those experiences alter a child’s values, beliefs, language, and problem-solving abilities. The reality for individuals who have developmental disabilities is that each person is unique in its entirety, yet when each individual and their individual supports are considered, commonalities begin to emerge (Baynard-Brak et al., 2021; Mello et al., 2016; Singh et al., 2019; Trout et al., 2020; Zhang & Eshghi, 2019). Commonalities surface through examination of lived experiences that represent shared phenomena, often characterized by recognizable patterns of causes and effects (Lincoln & Guba, 1985; van Manen, 2016). When phenomena were identified and examined, they provided evidence of the efficacy of comparable practices and might guide interventionists in addressing persistent problems at a more individualized level (Elen, 2020).

Epistemological Assumption

Epistemological assumptions describe knowledge gained from firsthand information obtained in the field (Creswell & Poth, 2018). Because I spent the most recent 12 years of my professional life in the proposed rural communities and engaged in each of these communities in multiple ways for years before entering my profession, I have firsthand experience with each of the various cultures in the region. I have lived and worked alongside, and sometimes directly with, students who have autism, their siblings, their families, and other caregivers. I have worked in local public schools, charter schools, and homes where students are homeschooled or attended micro-schools. In my experience, I have encountered caregivers who were insightful and proactive, as well as caregivers who were indifferent and passive. Because autism is associated with a triad of impairments of social interaction, communication, and imagination, each student with ASD will necessarily present with various levels of functioning and skill, which environmental contexts may influence (Florian, 2014). Evidence showed that students with autism learn best within the context in which a skill will be used (Callahan et al., 2017; Florian, 2014; Kauffman et al., 2017). Through this study, I hope to contribute to the body of knowledge about how teenage and young adult students with ASD can develop social skills by examining the lived experiences of their caregivers.

Axiological Assumption

Axiological assumptions are conditions and values that influence the researcher's perspective (Creswell & Poth, 2018). My life experiences have impacted my values and my condition. My journeys through childhood, marriage, motherhood, adulthood, education, entrepreneurship, and as a practicing professional inform my values. Those values have driven my decisions as an adult, significantly impacting my personal choices and my family of creation's condition compared to my family of origin's condition. An individual's agency allows for choice. Although young children and some individuals with severe cognitive disabilities cannot exercise agency over conditions in their lives, the typically developing population exercises their ability to choose how they will respond or react to the actions of others, what they will do or not do if given the opportunity, and even how they will feel about their circumstances. I believe God does not give His children more than they can handle. He also provides a way for them to grow to handle what is given. Because of my life experiences, I believe that information is power. When people have sufficient and accurate information, they have the power to make better choices that can improve their lives and the lives of those within their stewardship. By sharing caregivers' experiences, I hope to empower others by informing them and helping them better understand those lived experiences.

Researcher’s Role

As the human instrument in this study, I acted as the control to minimize the effect of other variables while observing social interactions. I had worked with some of the teenage and young adult students who were included in this study. In my work with students and their families, I did not have any authority over them, nor did they have authority over me; we were partners with our specific contributions. My role was as an observer and interventionist. While conducting this hermeneutic phenomenological study, I was an observer and interpreter. As I collected data through interviewing adult caregivers individually, in focus group discussions, and responses to journal prompts, I synthesized the data that I collected into themes that illustrated how the participants perceived the social development of their students was affected by participation in homeschooling and habilitation as a young adult. My experience as a Speech-Language Pathologist informed the design of this study through the development of the research questions, the interview questions, and the interpretation of the data as it applied to the development and practical use of social skills.

Procedures

Participant solicitation, data collection, analysis plans for each data source, and an explanation of how the study achieved triangulation are described in this section. Procedures were steps in preparation before data collection, including site permissions and securing Institutional Review Board (IRB) approval. Data was collected with IRB approval and proper permissions, consents, and assents first being collected (Appendix A).

Permissions

Upon receiving IRB approval, I obtained all formal permissions and informed consent from participants. Formal and informal conversations with gatekeepers were conducted to identify feasible sites during the proposal process (Appendix L). A non-profit foundation in the area was run by a board of directors who aimed to increase awareness and disseminate information about autism to assist families through some of the complexities of living with autism. They had regular contact with individuals and families living in the area and were affected by ASD. The non-profit foundation expressed an enthusiastic willingness to be part of my study. Upon receiving IRB approval, I was informed that my study's design did not require any formal approvals or consent other than of the individual participants.

Recruitment Plan

The total population of residents in the area was around 8,000 (United States Census Bureau, 2020). The population was approximately 0.1% of Arizona's total population of 7,303,398 people (World Population Review, 2022). The prevalence rate of autism in Arizona was reportedly 3.0% to 3.9%, higher than the national average of 2% (Anbar, 2022; Center for Disease Control, 2022; United States Census Bureau, 2020; World Population Review, 2022). The actual sample pool of adults working with teenage students with autism who were homeschooled or participate in a micro-school was unknown, as no central database tracked students who were homeschooled or attended micro-schools. However, my personal and professional familiarity with individuals and families within the communities informed my confidence in recruiting sufficient participants for this hermeneutic phenomenological study. In some cases, multiple adult caregivers who worked with a single teenage student with autism were likely to have different experiences and were interviewed separately to extract their personal experiences.

Initial participants were identified by known association with homeschooling and their relation to a child diagnosed with ASD using convenience and purposive sampling (Creswell & Poth, 2018). It was possible that students could be current or former clients of my professional practice. I gave each prospective participant an introduction letter about the study, reiterating the voluntary nature of their participation and that their participation, or declination to participate, would not affect our current professional or personal relationship. Additional participants were identified by referral from other participants through snowball, or chain, sampling (Creswell & Poth, 2018). Convenience, purposive, and snowball sampling was used due to the nature of the rural location, since large populations of a single-presentation type of autism were unavailable due to the sparce total population of the rural setting. Sufficient interviews were conducted to ensure saturation. Saturation was determined when sufficient information was gathered to depict the guiding theoretical framework, when new information stopped surfacing during interviews, and when interviewees began to refer the researcher to other key knowledge holders who had already been interviewed (Mthuli et al., 2021; Sebele-Mpofu, 2021).

Informed consent and assent were obtained before any data was collected. If assent could not be given verbally or in writing, it was assumed by voluntary participation. Participants were informed about the voluntary nature of the study and their right to withdraw at any time. Participants were also informed about safeguards that would be in place to ensure the confidentiality of the sites, participants, and students (Appendix P).

Data Collection Plan

Because “there is no method to human truths,” obtaining as much data as possible is necessary before an informed interpretation of such data can be made (van Manen, 2016, p. 30).

Keeping a reflexive journal throughout each stage of the study to document my reflections on the phenomenon allowed the data to remain untainted. Keeping a record of impressions as they morphed throughout the data collection and analysis process allowed an informed interpretation of the data as a whole and in parts (van Manen, 1997). To triangulate information and strengthen the reliability of the findings, at least three data sources were collected (Carter et al., 2014). This study's three primary data sources were journal prompts, individual interviews, and focus groups (van Manen, 1997).

Individual Interviews

By interviewing parents and teachers of students who had a diagnosis of autism and whose children were, or had been, educated for one or more years during the ages of 12 and 30 at home or within a micro-school, the personal, perceived impact of social skill development during that time was reflected in their lived experiences. Interview questions were open-ended and semi-structured to elicit the interviewees' personal experiences rather than lead the response too rigidly (Creswell & Poth, 2018). Individual interview questions can be found below and in Appendix G. Through their lived experiences and the perceived impact of homeschooling on the students' social development, themes of growth or stagnation emerged to illustrate how the experiences affected social skill development. Interviews allowed the researcher to "borrow other people's experiences and their reflections on these experiences to be better able to come to an understanding of the deeper meaning or significance of an aspect of human experience in the context" of the broader experience" (van Manen, 1997, p. 62). Interviews were conducted in person, at the participant's home, in a community setting that was comfortable to the participant, or via videoconference. Interviews were either audio recorded or audio and visually recorded, when videoconference was used and then transcribed for review and analysis. Appendix H contains a sample of a transcript from an individual interview.

Table 1 – Individual Interview Questions

Interviews began with a conversation establishing rapport between the researcher and the participant. I asked about family members, home features, or another known or observable topic. The following questions were used to guide the semi-structured interviews. An indication of how the interview questions aligned with the research questions is provided.

1. When did you begin your role of caregiving with your student? (age) CRQ
2. Describe early interactions between you and your student. CRQ
3. Describe social interactions you observed between your student and other people. CRQ
4. How does homeschooling fit into your life? CRQ
5. What influenced the decision to homeschool or micro-school? CRQ
6. What do you think is the most positive aspect of homeschooling/micro-schooling? CRQ
7. What has been the most difficult part of homeschooling or micro-schooling? CRQ
8. Describe any special education services that have been used to meet the needs of your student(s). SQ2
9. Tell me about interventions used to address communication or the development of social skills. SQ2
10. Describe how you feel homeschooling or micro-schooling has affected social skill development for your student with autism. SQ2
11. Describe social interactions at home. SQ1
12. Describe social interactions in the community. SQ1
13. What do community outings look like? (Examples may be used to prompt responses, such as the grocery store, Walmart, park, or post office) SQ1

14. What activities do you share? (Such as joining and stimming) CRQ/SQ2
15. What behaviors do you see in your student that reflect your interactions? SQ2
16. When you are not acting as caregiver, who do you spend time with? CRQ
17. Are there any groups you spend time with? CRQ
18. As a homeschool parent of a child with autism, who do you consider a model or mentor for yourself? CRQ
19. How do you envision life will look for your teenager with autism when they are an adult? (Guiding prompts, such as college, trade tech, employment, and independent living may be used.) SQ3
20. Describe challenges you face because of your rural location. CRQ
21. Describe the benefits of living in a rural location. CRQ
22. What else would you like to add to our discussion of your experiences with homeschooling a teenage student with autism? CRQ

The questions listed above were intended to elicit candid dialogue about a caregiver’s personal experiences with a student diagnosed with autism. The questions were intended to inspire the participants to reflect on their experiences in a way that could be described qualitatively, including the context, behaviors, and personal feelings evoked by recalling those experiences (Moustakas, 1994). These interview questions were not meant to direct the participant’s thinking but to allow a forum to explore their thoughts and feelings while responding to prompts to describe their experiences.

The interview protocol included responses to these questions to explore how homeschooling teenage and young adult students with ASD in the rural Southwest United States affected social skill development to identify effective practices in settings with limited resources.

After developing my questions, I had experts in the field review the questions through peer debriefing to check that my opinions, beliefs, and attitudes did not obscure the participants' perspectives or experiences and to ensure objectivity (Shenton, 2004). Refinements of my questions were allowed to be made to improve clarity and focus. As a final step to the interviews, member checks were conducted by providing each participant with a copy of their interview transcript to review to see if there were any changes that they would like to make.

Individual Interview Data Analysis Plan

Analysis of individual interviews began by transcribing each interview and reviewing the transcript's content along with peripheral notes taken by the researcher during and after each interview (van Manen, 1997). After transcribing the interviews and before data analysis began, informants were asked to read their interview transcripts to verify the information recorder's accuracy. The interview data was reviewed by first reading over all the transcripts, followed by writing notes to record my initial impressions using holistic coding methods (Saldaña, 2021; van Manen, 1997). Using the modified van Kaam approach, each transcript was read individually, carefully labeling relevant words, phrases, or sentences that might have been indicative of emerging themes by using an eclectic combination of attribute coding, In Vivo coding, and values coding methods (Moustakas, 1994; Saldaña, 2021; van Manen, 1997). While considering the individual interviews as part of the larger whole of all the interviews and peripheral notes, relevant words, phrases, or sentences could include any information for any reason but was most beneficial when coding and collapsing the codes into themes. The specific wordings from the interviews could indicate attributes and repeated ideas identified through causation and phenomenological coding methods. Atlas.ti software was used as an organizational tool to mark, organize, and notate words, phrases, and sentences of each interview and then combine that information into themes or categories during the second cycle coding method of pattern coding, as each participant's lived experience was synthesized for essences. A second member check verified that my emerging theories and inferences agreed with the experiences expressed by the participants.

Focus Groups

Focus groups allowed the researcher to simultaneously interact with several participants in-person or virtually (Creswell & Poth, 2018). A focus group typically consists of between four and six participants who are similar and cooperative, with each contributing their perspective by responding to questions and engaging in dialogue with others as they come to a consensus when responding to the questions that are posed (Creswell & Guetterman, 2019). The participants in the focus groups were anticipated to distill the essence of addressing social skill development in teenagers with autism when limited resources are available (Creswell & Guetterman, 2019; Saldaña, 2021). Focus groups were either audio recorded or audio and visually recorded when videoconference was used and then transcribed for review and analysis. Appendix J contains a sample transcript of a focus group interview. Due to the change in participant criteria after the first focus group had been conducted, two additional focus groups were conducted with the additional participants.

Table 2

Focus Group Questions

The following questions guided the discussion and elicited responses during the focus group sessions.

1. What is it like being a caregiver of someone diagnosed with autism? CRQ
2. How does autism affect your life? CRQ
3. How do people react to your teenagers' behaviors when in public? SQ2
4. What would you like the public to know about how it is to live and work with autism? SQ2
5. Describe your ideal vision about how your teenagers will transition to adult life. SQ3

The first two questions were intended to inspire reflection and promote participant discussion (Creswell & Guetterman, 2019). Questions three and four invited participants to describe and discuss commonalities and differences in social experiences with their teens (Miles et al., 2020). Finally, question five allowed participants to discuss potential goals, as they envisioned their teens with autism becoming adults with autism (Miles et al., 2020; Saldaña, 2021). Focus group questions can also be referenced in Appendix I.

Focus Group Data Analysis Plan

The focus group discussion analyses began using the modified van Kaam approach (Moustakas, 1994). The focus group discussions were reviewed by first reading the transcription, followed by writing notes to record my initial impressions using holistic coding methods (Moustakas, 1994; Saldaña, 2021; van Manen, 1997). After reading the transcription and recording my initial impressions, each quote relevant to the studied phenomenon was listed and grouped to achieve horizontalization through elemental coding methods of initial and descriptive coding. Reduction and elimination were followed by examining each quote and determining whether a quote was both important to the participants' lived experience and could also be reduced to a latent meaning by interpreting the affect connected to each quote (Moustakas, 1994; Saldaña, 2021). A quote was eliminated if it did not meet both criteria (Moustakas, 1994). The remaining quotes were then grouped together based on categories of underlying meanings, thus revealing themes (Moustakas, 1994; Saldaña, 2021). The emerging themes were compared to the data to ensure that they represented the intent of the participants and their lived experiences (Moustakas, 1994). Next, I listed themes from each participant to identify patterns, such as recurring and prominent themes across all participants to distill those commonalities across the group (Moustakas, 1994; Saldaña, 2021). Finally, common themes were synthesized to merge into a comprehensive understanding of the phenomenon (Moustakas, 1994). Marking, organization, and notations of each interviewee's words, phrases, and sentences was completed manually and with the assistance of analysis software when feasible. Pattern coding combined themes and categories (Saldaña, 2021; van Manen, 1997).

Journal Prompts

Journal writing prompts were intended to prime the participants' thinking to increase and improve reflective responses during the writing exercise and subsequent interviews (Van Manen, 1990, 1997). Journal writing prompts are below and in Appendix E. Journal writing had the added benefits of fostering self-discovery, resolution of problems, and discovering relationships that the participant might not have been aware of (Van Manen, 1997). Journals using narrative story writing, videos, and photography have offered researchers rich narratives from which to draw qualitative data and participants a medium with which they are comfortable (Creswell & Poth, 2018). Journal prompts were the first part of this study's data collection to trigger caregivers’ reflections on their experiences. Journal prompts were given up to one week before the individual interview was scheduled, and the journal entry was collected before the interview from most participants. The medium of journaling was not restricted. If the participant preferred visual media to document their experiences, they would have been transcribed and analyzed along with written journal responses.

Journal Writing Prompts

Prompt #1. Describe your journey as a caregiver of a teenager/young adult with autism.

Prompt #2. What would you like your community to know about your teenager/young adult with autism?

Journal Data Analysis Plan

Analysis of individual journals began by reviewing the journal’s content (van Manen, 1997). If visual journals had been submitted, they would have been transcribed before data analysis begins, and authors would have been asked to read their visual journal transcripts to verify their accuracy. A sample response to the journal prompts is in Appendix F. No audio/visual journals were submitted. The journal data was reviewed by first reading over all the transcripts, followed by writing notes to record my initial impressions using holistic coding methods (Saldaña, 2021; van Manen, 1997). Using the modified van Kaam approach, each transcript was read individually and relevant words, phrases, or sentences that may have indicated emerging themes were carefully labelled by using an eclectic combination of attribute coding, In Vivo coding, and values coding methods (Moustakas, 1994; Saldaña, 2021; van Manen, 1997). While considering the journals as part of the larger whole of all the journals and peripheral notes, relevant words, phrases, or sentences could include any information for any reason but was most beneficial when coding and collapsing the codes into themes. The journal's specific wordings could indicate attributes and repeated ideas identified through causation and phenomenological coding methods. Atlas.ti software was used as an organizational tool to mark, organize, and notate words, phrases, and sentences of each interview and then combine that information into themes or categories during the second cycle coding method of pattern coding as each participant's lived experience was synthesized for essences. A second member check verified that my emerging theories and inferences agreed with the experiences expressed by the participants.

Data Analysis

Themes were merged across the data sources after analyzing, coding, and identifying themes for each type of data using Atlas.ti software as an organization tool. Merged data was structured in a combination of analytical and exemplificative methods to both represent the lived experiences of each participant while "rendering visible the essential nature of the phenomenon and then filling out the initial description by systematically varying the examples" as I sought to balance the research context by considering both the parts and the whole (van Manen, 1997, p. 171). I organized information by an eclectic combination of coding as an exploratory method, attribute codes as a grammatical method, descriptive or In Vivo codes as an elemental method, emotion codes for an effective method, holistic codes for an additional exploratory method, and causation codes for a procedural method. I then organized themes using categorical and phenomenological codes, as broad brushstrokes would better enable me to identify nuances that contributed to the phenomenon (Saldaña, 2021; van Manen, 1997). Second-cycle pattern coding as a cumulative method helped me to condense data into themes, concepts, causes, explanations, and constructs to examine common themes and directional processes (Saldaña, 2021).

Trustworthiness

In 1985, Lincoln and Guba proposed qualitative terms that established the trustworthiness of a study (Creswell & Poth, 2018). These terms were synonymous with terms traditionally used in quantitative research but better reflected the goals of qualitative research. These qualitative concepts and terms included credibility, transferability, dependability, and confirmability (Creswell & Poth, 2018; Shenton, 2004). This section describes the measures I took to ensure the quality and rigor of this qualitative study.

Credibility

Credibility, synonymous with internal validity, refers to how the findings measure or test a study's intended purpose and accurately reflect the participants' perception of reality (Creswell & Poth, 2018; Lincoln & Guba, 1985; Shenton, 2004). The higher the study's credibility, the more accurately the findings may be generalized across similar populations (Shenton, 2004). Techniques that I used to achieve credibility included the development of an early familiarity with the culture of participating groups, triangulation of data collection, peer scrutiny and review, and member checks.

Development of an Early Familiarity with the Culture

Cultural familiarity influenced professional judgments and will be checked by peer scrutiny and member checks. Visits to local community events, homes, homeschools, and micro-schools within the target communities had assisted my familiarity with the investigated cultures. Interactions between myself and community members had improved trust and probably did improve their willingness to participate and speak frankly during interviews (Shenton, 2004).

Triangulation

In this study, I used three data collection methods to triangulate the collected information, sources of information, and theories that emerged in the data. By employing triangulation, I sought to gain insights into the background information to inform levels of social skill development in support of, or that contrasts with, the current perspectives of the participants (Shenton, 2004). The data collection methods that I used to fulfill triangulation included caregiver responses to journal prompts, individual interviews of parents and other caregivers of teenage and young adult students who had ASD and attended homeschool or micro-schools in their community, and a focus group consisting of the parents and caregivers who had been interviewed individually.

Peer Debriefing

Peer debriefing and scrutiny of the research project by colleagues and peers ensured a comprehensive perspective and a focus on the topic of investigation. Feedback was welcomed to check that my opinions, beliefs, and attitudes did not obscure the participants' perspectives or experiences while keeping the purpose of the study at the forefront (Shenton, 2004). Challenges to my assumptions improved my objectivity and the credibility of the study.

Member Checks

Member checks ensured the accuracy of the recorded interview transcripts and my theories or inferences based on the interviews and the resulting transcriptions. After transcribing the interviews, and before data analysis began, the participants were asked to read their interview transcripts to verify the accuracy of the recorded information. A second member check verified that my emerging theories and inferences agreed with their experiences. Members were asked to offer reasons for patterns that I observed. Accuracy of data was essential for correctly representing each participant's life experiences concerning theories and for the overall credibility of the study (Shenton, 2004; van Manen, 1997).

Transferability

Transferability is a measure of the extent to which the findings of a research study can be applied to other settings and populations (Lincoln & Guba, 1985; Shenton, 2004; van Manen, 1997). For this study, I sought to enhance the transferability of the findings for the social skill development of other teenage students with autism who live in other communities and in different circumstances. Variables of the specific contexts studied may be important to transferability to contexts sought by potential future readers of the completed study. The variables for this study were elucidated using thick descriptions when presenting the research findings to illustrate how the students' social skill development impacted their functional interactions with adults, children, and peers within their community (Shenton, 2004).

Dependability

Dependability shows that the findings are consistent and could be repeated (Lincoln & Guba, 1985). Descriptions of my procedures were comprehensive so this study could be replicated with other populations and in other geographical regions. Overlapping methods of journal prompt responses, individual interviews, and focus group interviews provided the opportunity to increase dependability. Dependability was accomplished through an inquiry audit, which occurred at Liberty University during a thorough review of the research process and the research products by the dissertation committee and the Qualitative Research Director.

Confirmability

Confirmability is a degree of neutrality or the extent to which the respondents shape the findings of a study of researcher bias, motivation, or interest (Lincoln & Guba, 1985). Although researcher bias was unavoidable, instrumentation decreased dependence on human skill and perception (Shenton, 2004). To ensure the confirmability of this study, to the greatest extent possible, I used triangulation, audit trails, and reflexive commentary as three different techniques to establish confirmability. Triangulation was used to develop a comprehensive understanding of the phenomena and to reduce the effect of investigator bias. Audit trail diagrams illustrated the course of decision-making throughout the research process. Reflexive commentary was employed through memos, compiled into a journal to bracket my biases as the researcher investigator, and inform the audit trail.

Ethical Considerations

All permissions and consent were obtained before beginning any data collection. Participants' identifiable information will be kept private. All identifiable information and collected data will be stored in a password-protected external drive, which will be kept in a locked cabinet in a locked office monitored by continual video surveillance.

Permissions

Before collecting any data in written journal responses, individual interviews, or focus group interviews, I obtained approval from Liberty University's IRB (American Psychological Association [APA], 2017a). Once IRB approval was granted, I sent out emails to potential participants. Upon receiving responses from potential participants, I obtained informed consent from the participants (APA, 2017a). All participants were informed of the voluntary nature of the study and their right to withdraw at any time.

Other Participant Protections

Participants were informed about the safeguards in place to ensure the confidentiality of participants by using pseudonyms for identifiable information about each participant and their locations (APA, 2017a). Physical and electronic data was and will be secured using multi-level security measures for at least three years. Physical data will be secured in a lockbox within a locked file cabinet in a locked office with perimeter security monitoring. When physical data must be transported, it will be secured in a lockbox placed in an obscured location within a locked vehicle. All electronic data was secured using password-protected hard drives and placed in the lockbox whenever not being actively used. The data is expected to be destroyed after three years, but if the researcher feels that the study may be extended, the data will be preserved. Potential risks to the research participants may include anxiety, misrepresentation, and identification of the participant in published papers by themselves or others (Richards & Schwartz, 2002). The risks will be minimized using audit trails, member checks, confidentiality practices, and reflexive analysis (APA, 2017a; Richards & Schwarts, 2002). Participants were offered no immediate or direct benefit; however, indirect benefits may have included participant reflection and introspection regarding their child's needs (Murray, 2003). Feedback, in the form of information about unknown services and interventions available to participants, may benefit participants and their students.

Summary

A hermeneutic phenomenological design was selected to study the adult perspectives of their lived experiences with a child diagnosed with autism and their social skill development while participating in homeschooling or local micro-schools (van Manen, 1990). The adult perspectives were obtained and triangulated through responses to journal prompts, individual interviews, and caregiver focus group participation (Creswell & Poth, 2018). Each data source was examined and then analyzed to identify and code the data to develop themes of grammar, element, affect, exploration, and procedure (Saldaña, 2021). Categorical and phenomenological themes were condensed into common themes to identify and interpret directional processes or patterns and the occurrence of phenomenological nuances that contribute to those directional processes or patterns.

CHAPTER FOUR: FINDINGS

Overview

The purpose of this study was to describe caregivers' lived experience of social skill development for teenage students and young adults with autism in the rural Southwest. This chapter includes descriptions of each participant and participant grouping. The data collected in narrative themes, charts, graphs, or tables, are presented by theme, outlier data, and research question responses.

Participants

Participants were initially identified by known association with homeschooling and their relation to a child diagnosed with ASD. Initial participants referred the researcher to other caregivers who met the stated criteria for the study, which were over 18 years of age, spent 10+ hours per week with students in the capacity of a parent, were extended family members, teachers, or paid providers. The initial number of participants hoped for was between 12 and 15; however, due to changes in homeschool status, the number of eligible participants identified was seven. Of those seven, six were available to participate. While the hoped-for number of participants was not reached, saturation was reached under the initial criteria (Mthuli et al., 2021; Sebele-Mpofu, 2021). Because Liberty University required a minimum of 10 participants, participant criteria were expanded to include young adults with autism who received formal or informal habilitation services to improve their skills in communication, self-care, and increased independence at home and/or in their community. Participants included parents, siblings, and grandparents. One participant served as a habilitation provider for one family while informally providing habilitation services for a grandchild who lived with her but received no formal intervention services.

Joy

Joy is a widowed grandmother who lived near her grandchildren. She cared deeply for each of her grandchildren and was especially close to her grandson, Levi, who had the diagnosis of autism. Since Joy was widowed, Levi often stayed nights at her home and would occasionally help her with chores. Joy was an outgoing, friendly lady who made the most of what she had and reported that she was content. She had deep concerns about how Levi would get along as an adult in the wider world. She participated in his homeschooling when he was younger and continued to engage with him regularly, working with him to use manners and be polite.

Tara

Tara was a mother of five children, all of whom she homeschooled. Her second child, Levi, had a diagnosis of autism. Tara knew Levi was slow at walking and talking, but he was a happy child. Autism was not broached until he was in the local school district preschool, which at that time was a ‘special needs’ preschool. He received the diagnosis of autism at age 14. Along with ASD, Levi had comorbidities that required physical therapy and special braces. Tara did her best to keep up with the demands of a busy household, homeschooling her children, and taking Levi to appointments with doctors, physical therapists, speech therapists, and for neurofeedback sessions. “Getting him services is hard,” says Tara, “we have to drive one hour just to get therapy because they don’t have much autism-specific therapy [locally]…and [figuring out] what takes his insurance, which places are in-network.” Most appointments required driving across state lines or up to 350 miles one-way within the state where her family lives.

Olivia

Olivia was a trained registered nurse and one of three mothers in a family with 23 children, of which Oliver, her son who had a diagnosis of autism, was the youngest. Five older children were diagnosed as being on the spectrum. Olivia was separated from her spouse and lived with Oliver and one other adult son with autism. Given the increased severity of the initial symptoms in her youngest, Olivia chose to seek out other options. With the support of her family and community, Olivia and Oliver traveled across the country to receive training in a specialized, autism-specific program with some of her family members. The program was a home-based program that prescribed a specific educational and developmental model to ameliorate the symptoms of autism (autismtreatmentcenter.org). Olivia shared, “I have older kids who don’t know how to do math, reading, writing, and they went to twelve-plus years of school. They’re in school and they’re three years old and graduate not knowing how to do third grade math…not knowing how to do second grade math, [or] how to write so you can read it.” Due to the experiences the family had with their older children’s education in public schools and Oliver’s strong refusal to attend public school in any form, the family made the decision to homeschool. Oliver “hated it. He hated all the noise, the kids, everything.” Through state-funded programs for those with developmental disabilities and state-level options to fund homeschooling, several of Olivia’s older children were paid to work with Oliver as caregivers and teachers. Olivia served as overseer for “the team” and communicated with each member regularly to facilitate continuity across locations and caregivers.

Evan

Evan was Oliver’s older brother. He was in his twenties when Oliver was born and, initially, did not have much to do with him. When Evan’s mother, Olivia, began to recruit family members to participate in Oliver’s intervention program, Evan learned the Son-Rise® methods and dove right in. Though several life changes occurred over the years for Evan, Oliver has remained a focus for Evan. Evan worked with Oliver as a paraprofessional in his homeschooling program and provided much-needed guy time.

Zona

Zona was Oliver’s older sister. Zona was considered the consistent one of Oliver’s team. She worked with him in several capacities over the 13 years of Oliver’s journey, including as a paraprofessional, teacher, and respite provider. During that time, Zona had six children of her own. Zona challenged Oliver. Her children were present when she worked with Oliver, and Oliver had to learn to manage his feelings, words, and actions toward younger children who were in his space. Zona was very tuned in to reinforcing desired behaviors and not reinforcing behaviors better extinguished. Oliver learned to advocate for himself largely because Zona was flexible and adapted to Oliver’s needs when reasonable. Oliver also learned to be more flexible and adapt to Zona’s needs, increasing his capacity to care about others.

Abigail

Abigail was also Oliver’s older sister. She was the closest to him in age and was actively engaged in Oliver’s treatment since he was born. From his birth, Abigail remembered thinking, “I want to always take care of him.” She also remembered, however, that Oliver was aggressive toward her when they were children – hitting, kicking, and biting because he liked it when she would cry. She vividly recalled, “One point where he had a knife from the kitchen, and I was scared because he had a knife, so I ran, and he ran after me with it!” After that experience, their family began to change things in earnest. Over the years and through many changes, Abigail and Oliver have developed a close relationship with each other. Abigail worked as a teacher in a nearby, but across the state line, Montessori school. Oliver could not attend the Montessori school, but Abigail brought many of the Montessori tenets to assist Oliver's team by acting as curriculum advisor. She felt that having grown up with Oliver helped her be better at her job as a teacher.

Anna

Anna was Zane's mother. She was married and obtained a one-year secretarial certification from college before Zane was born. Zane was 30 years old, non-verbal, lived with his family, and used a picture book to communicate many of his needs that were not clear to his family through familiar vocal intonations or other non-verbal cues. Zane was Anna's fifth child and needed continuous supervision. Anna had a younger son who also had autism and was non-verbal, but he passed away a few years ago. Anna attended many conferences and trainings during Zane's childhood. She spent years sitting with him in public school, private school, a community center, and their family home school. She regularly took Zane to his appointments and sometimes took him to run errands. Zane really enjoyed going for rides. When Zane was not with Anna, he was often with his sister, Zelma, who provided respite and habilitation services for him.

Zelma

Zelma was Zane's older sister. She was single and lived with her family. She provided respite and habilitation services for Zane most days of the week. Zelma was always very close to Zane as they were growing up and had a close relationship. After living and working away from home for several years, Zelma returned to work as Zane's caregiver. Zane loved to spend time with Zelma. They had long-standing dialogues and routines which Zelma used to incorporate communication and cognitive skills.

Violet

Violet was a widowed grandmother who lived in the same town as many of her grandchildren – several of whom were known to be diagnosed with autism. Violet ended her formal schooling in 10th grade – not knowing how to read or drive. Her husband helped her learn to read, to drive, improve her physical health, and to gain confidence in herself. For the first time, she felt like she was somebody. Violet passed that along to her grandson Timothy. Timothy had autism but was not diagnosed until he was in high school. He received some interventions, but Violet was not directly involved in his day-to-day life at the time, so she did not know what help he received. Timothy had been living with her since he was 22. During those five years, Timothy learned to drive, got his driver's license, and had a small truck and ATV to get around town. He learned to clean his own room, how to schedule regular baths, and got a job working at the local grocery store. Violet helped him with his banking, food preparation, and self-care while Timothy helped her with chores around the house. He was also learning to care for the animals. Two years ago, Violet became a caregiver to another family with three young men who had autism. Kenny, the oldest of the three, was 21 when she began working with him. She was teaching Kenny to read and to take care of himself and animals. Violet believed that the way to reach these young men was by just being their friend.

Vivian

Vivian was a mother of six, three of whom had a diagnosis of autism. Her first child, Timothy, was not diagnosed until he was in high school. Whatever symptoms he exhibited as a child were eclipsed by the symptoms of his younger brother, Thomas. Thomas was diagnosed with autism at age three. By age three, Thomas was not walking or crawling. Instead, Thomas would bum-scoot to get around. He never used functional verbal language to communicate.

Thomas would scream to get his needs met and soothe himself by rocking back and forth or flapping his hands. He was involved in the local early intervention program between the ages of 18 months and three years. Later, he attended a local school district Preschool, which, at that time, was a special needs preschool. Then, he attended the local public school, which at that time had the bulk of the administration, which had specific training in special education. Vivian worked with the special education director and vice-principal at the school, along with Thomas' therapy team, which consisted of a physical therapist, an occupational therapist, and a speech therapist, who worked with him at home, funded by a state-level, long-term healthcare program, to help Thomas improve in areas such as walking, potty training, alternative communication methods, and self-care. Thomas had been out of school for four years but continued to receive the home therapy services he had not aged out of, along with caregiving support provided by his parents and siblings. Vivian did her best to keep up with the demands of a busy household, which included two adult daughters, a teenage son with autism, and a younger son. She often took Thomas to appointments with doctors to try to identify and treat his seizures, along with both acute and chronic pains related to bone structure in his feet, including digestion problems. Most appointments required driving across state lines or up to 350 miles one-way within the state where her family lived. The local community recently opened a medical clinic, so now some of his needs can be addressed there.

Table 4

Caregiver Participants

Caregiver	Age Range	Highest Degree Earned	Caregiver Role	Relation to Student	Marital Status
Joy	61+	Some College	Respite provider, homeschooled student when younger.	Grandparent	Widowed
Tara	41-50	Some College	Primary caregiver, homeschooled student when younger.	Parent	Married
Olivia	51-60	College Degree	Primary caregiver, homeschooled student when younger.	Parent	Separated
Evan	31-40	Some College	Paraprofessional, homeschools student.	Sibling	Divorced
Zona	31-40	Some College	Paraprofessional, homeschools student, respite provider.	Sibling	Married
Abigail	18-30	Technical Certification	Sibling, Montessori teacher, curriculum advisor.	Sibling	Never Married
Anna	51-60	College Certification	Primary caregiver, homeschooled student when younger.	Parent	Married
Zelma	31-40	High School	Sibling, respite provider, habilitation	Sibling	Never Married
Violet	61+	Less than High School; Some College	Primary caregiver, respite provider, habilitation	Grandparent	Widowed
Vivian	41-50	High School; Some College	Primary caregiver, habilitation	Parent	Married

Results

Through analysis of the data, 527 quotes and over 200 concepts were identified. Those concepts were collapsed into themes that categorically represent those concepts. Three primary themes emerged to represent the experiences of participants who provide caregiving services to teenage and young adult students with a diagnosis of autism. The themes were caregiver resources, interventions, and social maturation.

Caregiver Resources

Caregivers access to resources – information, human, financial, and emotional – could be the deciding factor in the ultimate outcome of their student. According to Evan, caring for a child of any age who had autism, “basically changes everything.” Providing for the needs of the student with autism could become overwhelming to the caregiver who had many roles to fill, as Tara said,

> Because I have other kids, it just makes it really hard to equally distribute my time with them just because the child that has autism just generally, either wants to take all my time or has to take my time because of appointments and, you know, everything that comes along with it.

To which Anna added,

> A lot of times where it seemed like we were focusing just on him because of what was happening with him, and we want to be careful. We try to be careful not to let the other children feel neglected because he was getting so much attention. So that’s some of what goes with the family dynamic.

Elements of caregiver resources appeared across all three sources of data for eight out of 10 participants. In total, the codes which made up the theme of caregiver resources appeared 335 times in participant interview transcripts, journal prompts, and focus group transcripts. Caregiver resources were divided into four subthemes: emotional support, financial support, developmental supports, and support limitations.

Emotional Support

Every caregiver interviewed cited their adult support system as being primarily made up of family members and friends. Additional support included extended family members and friends from church. Two participants specifically cited friends who also had children with autism or other pervasive developmental disabilities. Being a caregiver "is basically a full-time job," shared Tara. Olivia added, "It takes a lot of patience and trying to be understanding." Vivian said, "It's very fulfilling, but it's very challenging." Anna continued, "You get to learn a lot of patience, a lot of self-control" and "it teaches you compassion, and I wish everybody had that."

Mentors were cited as providing emotional support by offering guidance and encouragement while following through with recommendations for developmental intervention services. Four participants said that other professionals (schoolteachers and therapists) helped them to better care for their student. Zona stated, "I have honestly been like so many times when I'm like, 'Okay, how would [therapist] react to this situation?' [and] I implement a lot of those into how I work." Three participants mentioned spouses or former spouses. Violet fondly recalled that her spouse, who was deceased, "taught me how to read and feel good about myself. He treated me like I was somebody. I was just a human," and Violet passed that along to both Timothy and Kenny by "just being their friends," teaching Timothy to be more independent, and "helping Kenny learn to read." Two participants recognized their parents as mentors that helped them to be better caregivers. Abigail, who was unmarried and worked a job outside of her caregiving role, was the only participant to cite coworkers as part of her support system.

Financial Support

Table 5 illustrates the characteristics of the teenagers and young adults who were cared for by the participant caregivers. In the Verbal Teenager quadrant, funding sources differed based on severity of ASD symptoms as young children. Those funding sources impacted the availability, location, and frequency of interventions and caregiver resources. Both teenagers lived in dependent-living situations, did not work at a job, did not drive, and required assistance for self-care, food preparation, medical appointments, and household responsibilities.

Table 5

Characteristics of Teenagers and Young Adults with Autism Cared for by Participant Caregivers

	Teenager	**Young Adult** (22 years or older)
Verbal	Dependent living situation (with parent or grandparent)	Dependent living situation (with parent or grandparent)
	Do not drive	Drive – 1 of 2
	State-funded education/home & community	State-funded interventions (speech habilitation, respite care, physical health) – 1 of 2
	Interventions (PT, Speech, mental health, physical health). Funding from different State programs.	Work a job or express the desire to work
	Do not work at a job	Require assistance for:

	Require assistance for: Self-care Food preparation Medical appointments Household responsibilities: trash, animals, cleaning bedroom, washing their laundry	Self-care Food preparation Medical appointments Household responsibilities: trash, animals, cleaning bedroom, washing their laundry
Non-Verbal	***No Caregivers of Non-Verbal Teenagers were Available for this Study***	Dependent living situation (with parent) Do not drive State-funded Interventions (speech, habilitation, respite care, physical health) Require assistance for: Self-care Food preparation Medical appointments Household responsibilities: none

There were no caregivers for Non-Verbal Teenagers available for this study. In the Verbal Young Adult quadrant, one of the two young adults received state-funded interventions. The young adult who did not receive funding for interventions or habilitation was on Supplemental Security Income (SSI). Both adults lived in dependent-living situations, one worked at a part-time job, one was licensed and drove a vehicle, and both required assistance for self-care, food preparation, medical appointments, and household responsibilities. In the Non-Verbal Young Adult quadrant, both received state-funded interventions, medical care, and respite for caregivers. Both adults lived in dependent-living situations, neither worked or drove, and both required assistance for self-care, food preparation, and medical appointments. Neither have regular household responsibilities.

When referring to Empowerment Scholarship Account (ESA) monies that were used to fund Oliver's education, Olivia passionately stressed, "It is absolutely critical that they continue to allow homeschooling… because I'm not a teacher." Tara and Olivia each discussed how having access to ESA funds was critical when choosing curriculum, paying tutors, hiring paraprofessionals, paying for testing and therapies, and providing other tools necessary for educating their child with autism. Tara said, "Once he got on ESA, then we primarily did tutors…so he has private tutors who homeschool through the ESA, so he's homeschooled by someone else." Access to these funds decreased the financial burden and increased the potential human resources for the families who were homeschooling children with autism. Gratitude for the ability to homeschool their student was abundant in the responses of those caregivers involved in homeschooling. ESA funding was essential for Levi, since he had not been formally diagnosed until he was in his teens, and his symptoms were considered too mild to qualify for the state developmental disability program. As in public schools, ESA funds cease to be available when the student turns 22 and has an active IEP.

Funding was provided to cover therapies, habilitation, and respite care for the four students who qualified for the state's developmental disability program. Most intervention services continued to be available beyond age 22. By decreasing some of the financial burden, the emotional well-being of the caregiver was improved and allowed more time to care for the rest of their family and their own needs.

Developmental Supports

Eight of the participants reported that having other adults who played positive roles in the students' lives decreased the stress on caregivers. These adult roles included: therapists, respite providers, service coordinators, teachers, paraprofessionals, tutors, neighbors, extended family members, grandparents, and siblings who had active roles in the student's life. By identifying adult roles and dividing them across multiple adults in the student's life, the teenagers and young adults with autism were reported by every participant to be more receptive to different types of teaching but could become confused about who did what in their life. Abigail stated, "Sometimes [Oliver] feels frustrated because we're his family and his teachers as well. I think that sometimes he doesn't really know [where] the line is between…okay, this is like sister-time, and this is teacher-time."

Support Limitations

Because of the rural location, options were limited. Olivia was frustrated that, "we can't send him to the Montessori [school] because it's …two blocks north of the [state] border." Olivia's family had a resource in Abigail because she was a Montessori teacher and brought her knowledge, experience, and ideas to Oliver's team, but not all families had that kind of team. Another frustration that Olivia conveyed was of "not having some kind of little convenience store" that he could walk to, which necessitated getting a ride across the busy highway. Caregivers who were not parents had financial concerns. Zona shared that,

Being in a rural area, it's difficult to get on and it's difficult to stay on [as a respite provider], and just getting the pay needed. I think in some cases, it isn't worth the effort it takes to apply…. if you're a respite care provider for a kid or two, that almost barely covers it.

Options were limited and finding providers who were a good fit for the student could be a challenge because,

> We’ve also got kind of an overload on providers. There’s not enough providers for these children who need the resources [and that] makes it difficult to get the amount of care [they need].

Zona further elucidated,

> A lot of the problem is availability to special resources. Whether or not the therapist wants to stay working with him or getting a better job [is] a pretty big problem,

because although most therapists’ caseloads were part-time, they were overloaded due to having to fill multiple roles that might be filled by employees in more urban locales, to continue providing services.

Interventions

Interventions referenced and utilized by caregivers for the benefit of their student with autism included educational, therapeutic, and medical resources which were obtained privately, through state-funded programs and community-based organizations. The subthemes of *Specialized Education* and *Planning for the Future* (a.k.a. – transition planning) were included within the theme *Interventions*. Elements of *Interventions* appeared across all three sources of data for most participants. In total, the codes which made up the theme of Interventions appeared 132 times in participant interview transcripts, journal prompts, and focus group transcripts.

Specialized Education

Autism’s hallmark features of aversive social interest and heightened sensory stimulation have resulted in myriad challenges that had to be addressed before learning could begin. Each of the students who was homeschooled had a different combination of needs and each set of needs was addressed by their families to increase their ability to learn. Along with heightened sensory stimulation, emotional regulation strategies that worked with one child were different for another. Emotional regulation activities (screaming, rocking, zoning, ism-ing, hand-flapping, among others) that were needed for the student to regain physical and emotional control of themselves would not be conducive to other students' learning or a teacher's teaching. One-on-one instruction, repeated until the student 'gets it' would not be a reasonable demand in a classroom setting, but in a homeschool setting, as Joy iterated,

> If it's done right, and the teacher's really focusing on exactly what's going on with the child, they can help, or just realize maybe we shouldn't even do this subject at all….It's just not good to keep pounding on him about something that really might not be something he'll ever understand.

Olivia said,

> I feel like that because of the rise of autism and [other disabilities], the school system is going to have to go to a small pod system if they're going to continue to actually help these kids because otherwise, you're just…shunting them through a system and out the other end and they don't come out knowing even close to the things they do in homeschool,

which was further validated by experience with her other older children who had autism and attended public school through their formative years. Olivia continued,

> Who else wants your kids to grow and be more able to cope? I have older kids who don't know how to do math, reading, writing… and they went to 12-plus years of school. They were put in school when they were three years old and graduated not knowing how to do third-grade math…and not knowing how to do second grade math…and how to write so you can read it…

Specialized education was necessary for Oliver and Levi. It was made possible with homeschooling and the ESA funding provided by the state. Homeschooling provided the flexibility to adjust their curriculum, start-times, and allow for pauses so the student could take care of their needs without interrupting the learning of a classroom full of other students. Olivia said that having the option to choose their own curriculum "[made] it so that he feels a lot more in charge of his day, so he kind of gets to help decide what's going on." Environmental adjustments (types of lighting, dysregulating sounds, physical positioning, isolating from other children, etc.) that were needed by one student were not practical in a large classroom environment and resulted in school refusal. Olivia stated, "He [Oliver] refused to go to school. He hated all the noise, the kids, everything." With homeschooling, their days were more flexible. Olivia cited that there was more "flexibility to adjust the schedule" and even to change the lightbulbs. Zona shared that she had more "flexibility in teaching methods." Evan added that the benefit was that adjustments could be made to provide a "low stimulation" environment, when needed. Joy remarked that sometimes flexibility is needed when you "just realize maybe we shouldn't even do this subject at all."

Regarding the social aspect of homeschooling, reports were mixed. Tara said,

> He [Levi] did well in the micro-school setting because it was small enough, he could get more one-on-one time without being so disruptive, but big enough that he was kind of forced to interact with other students.

She lamented that there were "no micro-school options for after eighth grade in the area." Olivia said that,

> I think we would have a bully on our hands who tried to survive the environment if it wasn't for homeschool [but] homeschool has provided the time and space to work with his feelings and emotions…homeschool has provided the time and space to become a nice young man, [and] now, when he's in public, he's able to treat people kindly and

> respectfully.

Abigail reflected that, “I feel [homeschooling] has held him back… there could have been more that we did, [although it’s been] helpful even though it’s lacking in diversity.”

Specialized interventions continued for the young adults who had autism. For those who qualified for the state’s developmental disability program, services that continued to be provided in their homes and in their community included speech therapy, occupational therapy, respite, and habilitation. While gains were slow, they have continued. Vivian said of Thomas,

> I do believe that he can learn more. I slowly tried to push him to learn more. I do believe the more consistent you are with him, even at age 25, he can still do…I see him, from time to time, step up and do more.

Planning for the Future

Caregivers, especially caregivers who were parents or grandparents, each expressed concerns about the future well-being of their student. Uncertainty about the employability and social acceptance of their student led to expressions of fear, such as when Olivia said,

> We, as parents, have to put things in place so that their life can be a little bit easier, but we have to also be realistic. They may never get married. What if they don’t get married? What have we done to put things in place for that kind of thing?

Olivia also said, “Who else wants your kids to grow and be more able to cope?” Olivia, Tara, and Vivian expressed, “What’s gonna happen to my child when I die?”, and Violet’s concern for her grandson, “I’m not gonna forever be here! I’m only good for another few years, you know?”

Parents and grandparents of children with special needs “want their child to be – to have the best life and the independence and that kind of thing,” said Evan. Zona’s statement,

> The ideal situation would be that he would be functioning enough to take care of his own finances, living conditions, and ask for help if needed. Or be able to set in place the help that’s required

was reflected by other caregivers of teens and young adults who were verbal. For those who were not functionally verbal, common sentiments expressed dependence on the child’s siblings or other extended family. Vivian shared,

> I see, as an adult, that he’ll probably have to have one of the siblings always be there to take care of him…or eventually, he’ll have to go to a home. I think he should be with somebody that can take care of him in a home setting. Yeah, instead of having to have him go to an institution or something like a facility that he has to feel like he’s at a hospital all the time. I think that would be really sad.

Parents and grandparents of both verbal and non-verbal teens and young adults expressed the desire for their child to have a small home or room in a home where they could be “somewhat independent, but he’s still got somewhere he can still be with family,” as Anna said. Zelma said she was concerned that Zane be “watched out for [and receive] mentoring and help [to] take care of himself and his needs.” For the verbal group, Tara listed additional resources to “hold down a job [and] find a group of friends,” while Zona talked about needing to “have help with scheduling and attending medical appointments [and] preparing meals,” and Violet expressed concerns about getting help to “deal with basic fears [and to] get help with his finances.”

Social Maturation

Social maturation encompassed the social awareness of other people, as well as the desire to be part of social groups – large or small – to *belong*. Olivia reflected Tara's sentiment by saying, "As our children grow, we need to be helping them understand the world around them but then the world around them to understand them." The desire for social connectivity was cited as increasing over recent years among teenage students and young adults with whom the caregivers worked. This development was cited as a product of observational learning through social exposure, adult modeling, and emotional regulation. Elements of social maturation appeared across all three sources of data for most participants. In total, the codes which made up the theme of Social Maturation appeared 79 times in participant interview transcripts, journal prompts, and focus group transcripts.

Modeling/Observational Learning

Modeling by a trusted peer or adult provided opportunities for the student to observe the social interaction(s) and to later review the interaction by discussing what the student observed. These observations gave the student a model to emulate. Shared activities were primarily reported as watching movies together, followed by going for drives, and hiking. Shared activities with a small group or one-on-one facilitated opportunities to initiate social connection, as voiced by Abigail,

> When we don't get to talk for a while, he'll like try to plan a time for us to get together and just talk with each other, 'I miss talking with you. When can you come over?' or, when can you do this or that?

As beneficial as modelling and observational learning could be, unrealistic expectations plagued those who were socially aware. Tara stated,

> As they grow, you know, and they're not really on the same level as the other kids, but they want to be, and they can see that they should be…

added to social pressures on both students and caregivers. Joy shared that Levi

> wants to get out of here as soon as he can [to] go and get a job and move…work at Subway and get an apartment. Live in the city…

While shaking her head, Joy continued,

> his cousin that is a little bit older than him says, 'Levi, that's not gonna work. They only pay $7 an hour at Subway and you're not gonna get anything,' but I don't know how this is gonna work. I don't…I think he needs to have a taste of being in town. I don't know…

Three participants expressed that their teenage or young adult was seeing their peers, their siblings, move on with their lives – driving, living on their own, going to college, building careers, getting married, having children – and they began thinking about those things too. Tara said of Levi,

> He won't let people help him because he basically just says, 'I don't need your help. I can, you know, when once I'm 18, I can just walk out the door and I'll go get an apartment, and I'll go, you know, get my car and I'll do my thing [because] he doesn't want anybody to know that he has autism. He doesn't like me telling people…he can see what he suppose…. what normal life is, and he knows it, but he doesn't know how to get from A to B.

Emotional Regulation

Along with modeling and observational learning, students needed ways to advocate for their own needs by having the choices that were available to them made clear, and the assurance that those choices would be responded to in a positive way. Oliver's family gave him option to partially participate when he was reluctant by asking, "'would you like to come with us long enough to see what it is and then if you need to leave, we'll leave'…and then we leave." Opportunities to exercise their self-advocacy in a safe environment increased their confidence when advocating for their needs in a novel environment or with people who did not know them well.

"Knowing the rules" was explained by four participants as key to emotional regulation at home and in community settings. Within a home setting, Joy shared that,

> We have certain rules [that] he can't get breakfast until he makes his bed up and straightens up and if he says bad words then I won't take him driving. He can walk the mile. One day was 22 degrees and he got the chance to walk…. he really doesn't fight me when I tell him these rules. He either goes along with them or he doesn't, and he's suffered the consequences and he's very nice about it. He didn't get angry.

In a community environment, Abigail said of Oliver,

> He'll like, talk to some of the kids that are coming by him and make sure that they know the safety rules. And, you know, he's like, 'Hey, you're you're getting kind of testy. Do that somewhere else,' which might be appropriate if he were an adult speaking to young children…he's very honest…very, very open.

Each caregiver described ways that their teen or young adult attempted to regulate themselves. Regulating behaviors were often referred to as zoning, stimming, or isming. These behaviors were all described as containing one or more of the following: rocking, singing, talking (intelligible or unintelligible), touching themselves (hands down pants, among others.), and hand-flapping. Social appropriateness was sometimes monitored by the teen or young adult, but usually required prompts or cues from the caregiver.

Outlier Data and Findings

There were two clear outlier findings that emerged during the analysis of the collected data. These outliers concerned the caregivers' anxieties about the teenager or young adult being placed in a group home and the stark differences between intervention accessibility based on the severity of early symptoms. Each of these concerns have been expounded upon in this section.

Outlier Finding #1

Of the adult participants, parents and grandparents expressed grave concerns about their student being placed in a group home or hospital-type institution. When asked how they envisioned life looking for their teenager when they reached adulthood, Joy responded that, "When I think about it, I just feel really sad. Is he gonna be put in some group home with a bunch of other ones who are not achievers and just, you know, just get lower and lower?" Each parent and grandparent expressed the need to ensure that their student become as independent as possible, yet still have help to navigate certain aspects of adult life – specifically self-care, finances, medical appointments, and personal safety. Access to perceived helps varied across participants based on the size and proximity of their own immediate and extended family members.

Outlier Finding #2

The second, and possibly most impactful outlier finding, is that children who presented with mild symptoms when they were very young may be more at-risk as they grow older. The risk lies in that their symptoms neither raise enough alarm to signal to parents or other professionals that they needed help, nor to those who determine qualifications for intervention services when those services were sought. Tara shared that

> Levi was diagnosed when he was 14. He was on [the State's developmental disability program] but he was denied [long-term care insurance which would pay for intervention services], so I took him off [the State's developmental disability program] because they wanted to do interviews every three months even though they never did anything to help or provide services.

Unsubsidized intervention services are expensive and may only be available to families who live in rural areas *if* there are qualified intervention professionals who also live in those rural areas. Tara explained, "We have to drive one hour just to get therapy because they don't have much autism-specific therapy [locally]." She continued, "The best places are in [nearest city in neighboring state] and that's hard too because where …what takes his insurance, which places are in-network." Families with limited resources are less able to provide services at a private level for their child who has any learning disability. They are also less able to access support for themselves, which may negatively impact the ultimate outcome of their child's development.

Research Question Responses

Responses to the central research question and three sub-questions collected during this study were outlined in the following section. The responses were collated, based on similarities of each caregiver's experiences. Answers were presented in summary form with in vivo quotes, where applicable.

Central Research Question

What are the caregivers' lived experiences of social interactions with their homeschooled teenagers and young adults diagnosed with autism? Caregiver's responses varied drastically between those who are parents versus those caregivers who are not parents. For the parents and custodial grandparent, responses to their lived experiences revolved around difficulties in obtaining services, getting to appointments, and flexibility especially when trying to balance the student’s needs with the needs of other family members. Non-parent responses reflected the benefit of fewer distractions, being able to talk about frustrations, regular re-evaluation of personal beliefs, and catering to the needs of the student. Both parent and non-parent groups mentioned safety as a benefit to living in a rural location, patience, and common activities of watching movies together, hiking, and going for drives.

Sub-Question One

How do caregivers describe their students’ social interactions with family members? Teenage and young adult students with autism were reported to recognize boundaries within the family context, as evidenced by Joy’s declarations that, “He always tells me, ‘thank you’ [and] he doesn’t fight me when I tell him the rules.” Zane, who is functionally non-verbal, would say “goodbye goodbye,” when leaving home, an appointment, or even the grocery store, yet, Zelma said,

> He doesn’t just look up and acknowledge [other family members in the home]. I will point them out. I’ll try to keep him, you know, thinking of others too, so that it’s not just all him.

Vivian, speaking of Thomas, who was also non-verbal, would

> come out of his room and sit on the couch or his rocking chair and, if he wants, he doesn’t really interact with us, but he will sit there and hover over us and watch us play, if he’s interested,

which was reflected in the fully verbal Levi who, as reported by Joy, “sits back and doesn’t really participate. He listens and watches, and once in a while, he’ll yell in a comment.” Contrastingly, Abigail and Evan talked about how Oliver began to “[initiate] conversational topics that we regularly engage in.” Students were reported to imitate behaviors they observed around them within their home, whether combative and argumentative or teasing and bantering. The over-arching drive was trying to get what they wanted and the way they got it was by imitating behaviors they witnessed, or by repeating behaviors that worked in the past. Tara and Joy described that drive as being “super hyper-focused on himself and his own needs [although] he’s…generally very pleasant to be around and helpful, so long as he’s getting something out of it.” Violet said, “He [Timothy] likes to play his games while he’s eating [in his bedroom]” and he considered what types of foods he would eat while gaming so “he don’t get his hands all dirty,” yet bathing his body or cleaning his bedroom only became a priority after incorporating a calendar and starting a job. These intense myopic interests excluded the interests of other family members, which behavior carried over into social interactions within community settings for those who are verbal and non-verbal.

Sub-Question Two

How do caregivers describe their students’ social interactions in community settings?

Teenage and young adult students with autism were reported to display signs of over-stimulation, which were socially inappropriate or misunderstood by others in the community. Tara said, “We have cues…signals…” to remind them to “get your hands out of your pants.” Evan spoke about “when he starts zoning or ism-ing, they’ll stare at him. Like one lady, we were at a function, and I just let him zone and I knew he was just relaxing, but she thought he was stressed.” The zoning behavior included hand flapping while rocking his body forward and backward and making a humming noise. Olivia commented that, “I think [other people are] just curious and kind of wigged out sometimes.” Evan shared, “it probably makes it more difficult on the parents of the kids than the kids themselves because the kids don’t know any better.” Olivia said, “As our children grow, we need to be helping them understand the world around them, but then the world around them to understand them.” Zoning or ism-ing may be harmless in some, but physiological concerns may become safety factors when, as Anna said, “we have to be careful when we’re walking by other people, because with his blind left eye and sometimes he doesn’t have [them] in his vision” – the blindness was caused by repeated trauma to that eye during his version of ism-ing. Anna and Zelma said that their family

> always let[s] them know that [Zane’s] got special needs and maybe they know somebody, or they deal with somebody that has something similar, so they relate. Quite a few of them do.

Social initiations and responses were reported for each teenager and adult, whether verbal or non-verbal, if you knew what to look for. For example, Vivian said that Thomas would “put his hand out sometimes, because we worked with him on shaking hands, but now he’ll just go put his hand out and that’s his way of saying, ‘hi’”; Anna said that Zane would join in a handshake and say, “goodbye goodbye” to indicate or agree that he was finished and leaving; Levi, Timothy, Kenny, and Oliver would each reciprocate farewells and sometimes initiate greetings. Oliver was working on skills that helped him repair conversational misunderstandings. Abigail said, “If he thinks he said something rude or in a rude way, he will try to apologize and clarify.” These social skills may vary in presentation, but they were emerging social skills. As Zane’s and Oliver’s families demonstrate, “most people are considerate” and “most of the time, I think they’re fairly understanding” because “we always let them know that he’s got special needs.” This mutual understanding is likely facilitated through living and socializing in small towns, but at some point, they may find themselves in unfamiliar settings where they, and their behaviors, are not well understood or accepted. None of the teenagers or young adults appeared to notice or to care whether those around them approved of their behaviors. The concern about behaviors and the effects of those behaviors were primarily their caregiver's. Most of the caregivers realized that the perception of other people affected the opportunities for acceptance and inclusion. In the cases of a teen or young adult obtaining and retaining employment, acceptance and inclusion was very important. Violet said,

> I asked Timothy how his interview at [the grocery store] went and he told me that, 'It wasn't gonna work out. They don't want me.' I had to go meet with the manager to find out why." She told me that he smelled bad and that he had said he wasn't going to wake up early or go to work every day. After we talked about it for a while, she understood that he needed consistent hours because he has trouble with shifting times. She agreed to give him consistent hours and I promised he'd take a bath.

Violet made sure that Timothy's baths were written on his calendar and that he took a bath every night before he was scheduled to go to work. Violet beamed, as she said, "He's doing really well at his job now and will talk to people at work."

Sub-Question Three

As a more knowledgeable other (MKO) in their student's life, how do caregivers ensure their student reaches an appropriate zone of proximal development (ZPD) to live as independently as possible? Each caregiver of a verbal teenager mentioned that their student "is a city boy" or "wants to live in the city." While that may be evidence of having grown-up aspirations, the reality was that the allure of being *grown up* and *independent* was not reflected in their abilities to take care of themselves in the most basic ways (bathing, cooking, cleaning, among others.), nor in earning or managing money. Olivia said of Oliver, “He wants money but he’s not sure that he wants a job,” which belied the notion that living in a new, unfamiliar city with fewer familiar community members, more environmental stimulation, and grown-up demands would require. Tara said,

> I would say [we] have a perspective about what their capabilities are and more of an emphasis on them being a successful part of society. And that even though they’re different, that they do have a lot of strengths and abilities and just more willingness to, I guess, hire and work with people who are autistic and give them a chance. Just because, you know, otherwise…you know, you’re just basically stuck being a caregiver forever if the…if society can’t learn to integrate and accept them and use their abilities rather than focusing on their disabilities.”

The concern that “having a place for them is super important, to “be able to learn, learn essential skills, be able to enter the workforce,” and “living on his own and not in a group home” or “an institution” was strongly stressed by every parent and grandparent caregivers in this study. Although several methods, techniques, and practices were described, caregivers commonly cited specific methods used to ensure improved independence, including speech therapy, adult mentors, hiking, and church or community activities.

Summary

Caregivers, especially caregivers who were parents or grandparents, expressed concerns about the future well-being of their student. Uncertainty about the employability, self-care skills, and social acceptance of their student led to expressions, such as when Olivia said,

> We, as parents, have to put things in place so that their life can be a little bit easier, but we have to also be realistic. They may never get married. What if they don’t get married?

> What have we done to put things in place for that kind of thing? Who else wants your kids to grow and be more able to cope? What's gonna happen to my child when I die?

Evan said that parents of children with special needs "want their child to be – to have the best life and the independence and that kind of thing." On the flip side, caregivers expressed their ideal vision of their student's future, which highlighted skills that they are currently, or will be, actively working toward. Zona said,

> The ideal situation would be that he would be functioning [well] enough to take care of his own finances, living conditions, and ask for help if needed, or [that we will] be able to set in place the help that's required.

The idea that an assisted living situation would be desirable when the family was no longer able to provide the support necessary was expressed wholly by parents and grandparents.

CHAPTER FIVE: CONCLUSION

Overview

The purpose of this study was to describe caregivers' lived experience of social skill development for teenage and young adult students with autism in the rural Southwest. Discussion and interpretation of thematic findings was followed by the implications for policy and practice, discussion of empirical and theoretical implications, limitations and delimitations of this study and its design, followed by recommendations for future research and a final summary of this study. Chapter Five consists of five discussion subsections: (a) interpretation of findings; (b) implications for policy and practice; (c) theoretical and methodological implications; (d) limitations and delimitations; and (e) recommendations for future research.

Discussion

The themes of *Caregiver Resources*, *Interventions*, and *Social Maturation* were discussed in light of this study and from the perspective of the researcher. The purpose of this section was to discuss the study's findings and the developed themes. The discussion section has five major subsections, including (a) Interpretation of Findings; (b) Implications for Policy or Practice; (c) Theoretical and Empirical Implications; (d) Limitations and Delimitations; and (e) Recommendations for Future Research.

Summary of Thematic Findings

The themes of *Caregiver Resources*, *Interventions*, and *Social Maturation* emerged in this study after the parameters of the study were adjusted to include caregivers of young adults who have autism. Responses to journal prompts, individual interviews, focus group interviews were analyzed. The analysis revealed a strong sense of available resources for caregivers and their charge, along with the challenges in obtaining those resources; interventions, which included resources, methods, and techniques were the second most discussed; and social maturation concerning emotional regulation and social integration were the third.

Caregiver resources included activities that the caregiver engaged in for their own social and emotional well-being to address their feelings of social isolation through personal, one-on-one relationships with family members or friends – some of whom also had a child with a disability, and groups of friends, online support groups, and church groups. Access to resources, such as medical services, medical specialists, trained intervention professionals, and options among available caregivers who might be the best fit for their child were reported to be very limited due to their rural location. Financial resources to assist caregivers encompassed paid habilitation and respite providers to allow parents to step away from their responsibilities as caregivers for their child with autism on a regular basis; funds to pay for homeschooling and interventions not covered by a different program for school-aged students; funds to pay for medical and therapeutic interventions, along with the habilitation and respite care, for each teen or young adult who was on the state's developmental disability program.

Interventions included specialized education, intervention services, and planning for the future. Interventions used by each teenager or young adult was different, based on the family's resources and the student's needs. Caregivers who were involved with homeschooling worked with students who were under the age of 22. Caregivers of students who were over the age of 22 received interventions under the term 'habilitation.' Both groups included interventions to develop improved communication, self-care, and life skills. All participants were directly involved in homeschooling, habilitation interventions, or both.

Social Maturation included emotional regulation, observational modeling, and the desire to have social connections. Homeschooling was described as beneficial because it provided the flexibility to adjust their curriculum, start-times, and allow for pauses so the student could take care of their needs. Self-regulation behaviors varied across caregiver's experiences, with some overlap. Each participant described strategies that worked for their student and how those behaviors and strategies were received by people in their homes and community. Observational modeling was noted as a critical factor when developing appropriate social skills. Purposeful modeling and guidance by more knowledgeable others (MKOs) helped the students have more positive interactions in their homes and community. Their rural location contributed to those positive interactions because there were more people in their community who were familiar with the students and their families. Those familiars offered communication opportunities and assisted when safety needs arose as the caregivers and students frequented public places. The desire to have social connections was reported to increase with age, as reported by eight out of 10 participants. The desire to *go* was clearly expressed across all participants, whether the student was verbal or non-verbal. Caregivers of every student who was verbal shared their student's desire to do what they saw others their age doing – driving, working jobs, living in their own places, and getting married.

Interpretation of Findings

This study was designed and conducted with a hermeneutical phenomenological framework. The researcher, an interventionist in the field of Speech-Language Pathology for over a decade, interpreted the findings through the lens of home and community-based interventions. Interpretations were informed by participant responses, observation, professional experience, and the current literature.

Natural Environments and the Self

Everything begins at the beginning. To understand what the caregivers of these teenagers and young adults have persevered and achieved, their early years cannot be overlooked. Because young children who have delayed communication and social skill development are at an increased risk for problem behaviors, such as increased aggression, withdrawal, low compliance, and poor social skills, early intervention is essential (Gray et al., 2008; Irwin et al., 2002; Janus et al., 2019; Zhang et al., 2017). A delay in service delivery can postpone the initiation of interventions indefinitely, depending on the severity of symptom presentation and a family's eventual awareness of resource availability (Gadow et al., 2017; Rossetti et al., 2020). Although the public schools in every state are tasked with the education of children from three to 22, the child's natural environment remains their home, their neighborhood, and their community.

Children with autism need the time and space to be *okay* in their own bodies and in their own homes before other environments and other groups of people, besides their family and intervention providers, can be assimilated. Their home was typically the ideal place. Parents needed coaching from interventionists to help them create a calm, soothing environment for their overstimulated child. Even within the home, a space that is considered *theirs* may be important – whether it is a room, a chair, or a space under a blanket, a quiet space where the visual and auditory noise can be blocked for a time could offer the opportunity to reset themselves emotionally and physically. Parent caregivers who participated in this study described how each of their children responded to stimuli; each was different from the other, even when there was more than one child with autism in the same family. As experience and the literature about autism shows, children are less able to filter extemporaneous input, such as lighting, noise, movement, among others. The aversive behaviors that develop may be simply coping mechanisms used to override the overload. The common need was the need for consistency in their environment and their caregivers. Homeschooling might be a way to maintain consistency in the child's natural environment and with their caregivers as they develop self-regulation skills along with academic learning. The family's homeschooling program would likely have to be altered as the child matured, but the changes could be done in a way that facilitated further growth rather than destabilization.

When caregivers provided their child with the time and space to reach calm, as they became teenagers and young adults, they were better equipped to manage their impulses and aggressions. Another benefit to becoming more self-aware was that the teenagers and young adults learned ways they could advocate for their own needs in more socially appropriate ways.

Readiness vs. Age-Appropriateness

Rather than moving a child through grade levels and different schools, a homeschool could be structured in a way that advances with the child's readiness for the subject or the next level. Advancing only when a concept was attained might take longer, but if it decreased future experiences with failure, it could be worth the extra time. Experienced caregivers and interventionists would likely agree that trying to make a child who has autism behave or accomplish tasks like a typical child might be expected to, is an exercise in futility. It is not going to happen unless, and until, their physical and emotional needs have been addressed.

Comorbidities are common in people who are diagnosed with autism and should not be overlooked when they are children (Brooks, et al., 2021; Doshi-Velez, et al., 2014). Comorbidities of anxiety, mood, psychotic, trauma, stress-related disorders, substance use disorder, and suicide attempts in adults who have autism are well-represented in the literature (Brooks et al., 2021; Dell'Osso et al., 2018a; Dell-Osso, 2018b; Kalb et al., 2016). Perhaps these comorbidities that have been shown in adults with autism could be decreased or eliminated by providing environments that are more conducive to the child's needs when they are young. Figure 1 shows a version of social circles to illustrate the process of communication and social relationship attainment.

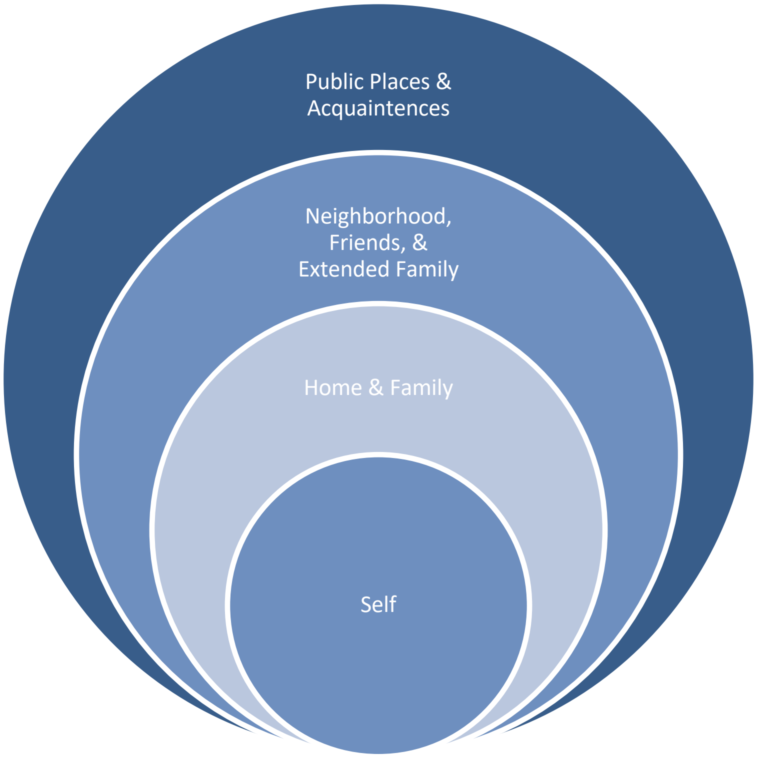

Figure 1. Social Sphere Model of Communication and Social Relationships

At the core is the self, the child, and their immediate needs, but realistically, the child's immediate needs will involve their home and family. In the process of families attempting to either 'deal with' or help their child, their home and each member of the family will undoubtedly be affected. The development of social skills may be best facilitated within the safe, highly familiar, and highly predictable home first. A family-centered approach to providing early intervention in a child's natural environment was essential because the family was a constant in a child's life, and interventions could be incorporated into frequently occurring daily routines (Movahedazarhouligh, 2021; O'Brien et al., 2019; Wergeland et al., 2022; Witwer et al., 2022).

Family members tended to be best suited to support the development of their children when they had the resources and support that they need (O'Brien et al., 2019; Wergeland et al., 2022; Witwer et al., 2022). In-home support services were ideal, as they enhanced caregivers' competency and strengthened the family. To avoid disrupting family activities and routines, intervention efforts were embedded into daily activities and routines, which then became a regular and natural part of those routines (O'Brien et al., 2019; Simmons et al., 2022; Wergeland et al., 2022; Witwer et al., 2022). By simplifying the child's environment, it may allow the child to develop selective attention through desensitization and predictability. For example, the hum of the refrigerator – it cycles on and off, but it is constant. When a family gets a new refrigerator, they might notice the hum is different for up to a few days, but eventually, it can be ignored because it is constant and predictable. Regular or frequent changes in the child's environment each day – home, school, daycare, grocery store, car rides – present myriad varieties of sensory stimulation that was continually changing and may preclude their ability to adjust and regulate themselves.

Caregivers, particularly parents, of young children who were diagnosed with autism are often not prepared to know what to expect or what they can do. Some caregivers, as emerged in this study, sought help early while others did not. Perhaps they did not know there was something wrong or they did not know that they could get help for themselves and their child. Vivian appreciated a special education director who directly questioned whether she was ready for her elementary-school-aged son to be potty trained. Given some discussion, Vivian recognized that unless she, as the parent, was ready to do what needed to be done, potty training would not be successful. Interventions and education may need to be based on readiness of the parent and readiness of the student rather than typical expectations based on age.

Resources available in rural areas change with time. While in the case of Anna's child, there was a community-run resource specifically for schooling children with special needs. That resource was limited to a specific faction of the community and dissolved as that part of the community stopped having children and moved to other cities and towns. When Vivian needed help with her second child, a program called Early HeadStart was available in her community, which facilitated early interventions and help with getting a diagnosis. Although there were Early HeadStart and HeadStart programs available in two of the incorporated towns in the area, at the time of this report, there was only one Early HeadStart available in the state, across a 135-mile stretch. That might mean that families may truly not have more knowledgeable others to help guide them.

Expanding Social Skills with Maturation

Self-regulation was the core of the diagram (Figure 1) because it was the core of social interactions. If the child was unable to self-regulate within their home and with their family, they would be unprepared to interact with other people in other environments. With time and successful experiences in self-regulation and self-advocacy, came predictability within their routines. Within those predictable routines, teens and young adult's interest in other people can have a solid foundation.

As their child matured and received the supports, they needed through their teenage years or even as late as during their young adult years, caregivers attested that the social skills of their teenaged or adult child with autism also matured. Violet, who Timothy began to live with at age 22, continued to help her grandson with reading, self-care, food preparation, medical appointments, and household responsibilities, but she also helped him to get his driver's license, obtain a vehicle, and secure a job. His social circles were expanding along with his self-confidence. Awareness of their peer or sibling life changes was not noted in those who were non-verbal, but it was readily apparent in those who were verbal.

Implications for Policy and Practice

Due to the increasing prevalence of autism, which was over 2% of 8-year-old children in the United States, the projected annual cost to U.S. taxpayers is $461,000,000,000 by 2025 (Anbar, 2022; CDC, March 2022; Rogge & Janssen, 2019). More alarming was the prevalence rate of autism in Arizona, which was reportedly 3.0% to 3.9% - higher than the national average of 2% (Anbar, 2022; Center for Disease Control, 2022; United States Census Bureau, 2020; World Population Review, 2022). If society does not find a way to bridge the communication and social skills gap for children with autism so that they can enter adulthood as more-fully participating members of their communities, taxpayers may bear the crippling economic burden of an increasing number of vulnerable adults, while the number of working adults dwindles in communities across the nation. Perhaps more importantly, mental illness and depression may consume those vulnerable adults unnecessarily. Current policies and practices were not designed to keep up with the increasing needs of those with autism or those that care for them. Policymakers need to be aware of this pending crisis and take steps to mitigate the economic and human costs. Policymakers, however, are rarely *in the trenches* and need accurate, current information from administrators, teachers, doctors, and specialized interventionists to guide them in determining the best practices. This section includes both Implications for Policy and Implications for Practice to help guide policymakers and to directly serve this population most effectively.

Implications for Policy

Autism spectrum disorder, by definition, encompasses a full range of symptom severity. This means that one answer, one solution, may not be sufficient to address the myriad problems that face those with diagnoses of autism, their caregivers, or the United States taxpayers. It may be advisable to approach this conundrum from multiple angles. First, tend to the current population of those in need. Second, plan for the future education, employability, and mental wellness of those who are able to work. Third, seek answers to the cause of ASD to decrease the prevalence rate in future generations.

Address Current Needs. Current needs of those who have diagnoses of autism and their caregivers must remain a priority and many positive policies and practices are already in place. Many states provide homeschooling options for families with students who have disabilities; however, not all parents are willing or able to provide the time and effort necessary to implement homeschool for their children. For those that are, continuing to allow funding that would otherwise go to the public school will be necessary. Intervention teams, who work directly with the parent(s), student(s), and other professionals to monitor progress on academic, physical, emotional, and social development may be advisable to ensure the best outcome for each student.

Interventions provided in the child's home and community beyond age three are shown to have increased generalization. Incorporating interventions into routines helps to generalize skills more quickly than if the activities were completed only during therapy sessions. Every family is unique, so individualized intervention strategies are necessary to address their circumstances and requirements (Kikas et al., 2016; Miller et al., 2017; Simmons et al., 2022; Wergeland et al., 2022).

Increase Employability to Decrease Mental Illness. The future of education, employability, and mental wellness of those who are able to work may be interrelated. Since ASD was not considered a curable condition at the time of this study, addressing the social aspect of the disability in a way that increases an individual's ability to interact with other people may allow each to reach their full potential by increasing employability while decreasing the likelihood of developing additional comorbidities, such as substance abuse, adverse behaviors, and mental illnesses (Anderson et al., 2020; Anderson et al., 2021; Dell-Osso et al., 2018; Sam et al., 2020; Sam et al., 2021; Solomon, 2020; Zweers et al., 2021). Policies that provide encouragement for people with autism to be employed, as they are able, have been shown to improve social development, self-confidence, and a decrease in self-harm or mental illness (Anderson et al., 2021).

Seek to Find the Cause and Abate ASD for Future Generations. The cause(s) of ASD were not known at the time of this study. There have been many studies conducted by intellectuals and professionals in the fields of medicine, education, and child development. There were even studies that have been conducted by agricultural and cultural researchers. With the data that was already collected, it may be possible to draw working hypotheses and begin to test their hypotheses, if only these experts had a forum to share their findings and the impetus to find answers and solutions to this worldwide enigma.

Implications for Practice

Policy alone cannot solve the dilemma of poor outcomes for people with autism (Dell'Armo & Tasse, 2019; Dell'Osso et al., 2018a; Dell'Osso et al., 2018b). Because ASD was a disorder that includes a spectrum of symptoms and severity, it was impractical to assume the abilities or outcomes for each person who was diagnosed. While there were circumstances of greatest severity that would preclude active employment or engagement within the community, such as cases that would have most likely qualified squarely within previous descriptions of autism in previous editions of the Diagnostic and Statistical Manual of Mental Disorders (DSM), caution must be exercised so that individuals with mild or moderate presentation of symptoms and severity are not excluded from active community engagement due to misconceptions based on previous diagnostic criteria or discomfort when interacting with persons with ASD due to poorly developed social skills. Implementation in practice needs to keep pace with the literature. Improved access to the literature, trained and informed professionals involved in parent support groups, and in-home provision of therapies are likely to help close the gap between current practices and evidence-based practices.

Improved Access to the Literature. Practices identified in the literature were intended for implementation to inform best practices. That sounds fine in theory, but in practice, it can be cumbersome. The primary problem was access to the literature, followed by the copious amount of time required to comb through the literature to find resources and practices that best fit the student and their situation. Access to studies can be quite expensive ($40/report) if the parent or practitioner was not affiliated with a university or other large organization that provided access through their institutional licenses. Since reading the studies was necessary to know if it was applicable, the parent or individual practitioner might have purchased copies of several studies before they located studies with information that they could implement. This was wasteful of time and money on the part of those who could afford it the least. An open-source site, like a public library, might be an answer.

Professional Involvement in Parent Support Groups. Positive responses by professionals involved in parent support groups might help offer accurate information which parents and other caregivers might not be aware. Although most professional interventionists have full calendars, a little information to these kinds of groups could go a long way to support families who are new to the world of disability, as well as families who are veterans. Parents and other caregivers of people with disabilities share what they know with other parents and caregivers – at medical appointments, therapy appointments, on social media, in waiting rooms, and in the line at the grocery store. Accurate information might clear up misconceptions about specific therapies and treatments while ensuring more accurate expectations among parents and caregivers. These groups might meet in person or online, giving the professional some flexibility when they are invited to be part of the conversation.

In-Home Provision of Therapies. In-home provision of therapies facilitates incorporation of interventions into routines which may help generalize skills more quickly than if the activities were done only during therapy sessions. This was a practice use by Early Intervention services but may be more beneficial if it were implemented generally. Every family is unique, so individualized intervention strategies are necessary to address their circumstances and requirements (Kikas et al., 2016; Miller et al., 2017; Simmons et al., 2022; Wergeland et al., 2022). Interventions in the child's natural environment may have the added benefits of decreased stress on the caregiver to take their child to another location for services, along with utilizing the social sphere model of strengthening the child's self within their home and alongside their family before moving to the outer rings of communication and social relationships (see Figure 1).

Empirical and Theoretical Implications

According to the theory of social constructivism, the ideal practice would involve parents, caregivers, teachers, and administrators who worked together with a child to ease transitions between school years, schools, or school levels, such as elementary, middle, high school, and postsecondary settings. The adults who worked together could regularly communicate about events or circumstances which might have influenced the behaviors or participation of a child and work to increase the child's sense of belonging and likelihood of experiencing success during transitions (Epstein, 2011; Lee et al., 2020; Ruble et al., 2019). However, there are some impediments that may create obstacles that stand between ideal practices and what was currently practiced.

A 2020 study conducted in every inclusive public elementary school in Kuwait revealed an "urgent need to provide training in IEP processes of development, implementation, and evaluation for all special education teachers" (Al-Shammari & Hornby, 2020, p.179). Pre-service and in-service teacher training for all teachers, including special education teachers, was essential for developing meaningful and attainable goals on Individualized Education Plans (IEPs), appropriately implementing plans, regularly evaluating student progress through consistent data collection to determine the efficacy of the interventions, and making adjustments when needed (Al-Shammari & Hornby, 2020; Iovannone & Anderson, 2022; King et al., 2018; Swain et al., 2021). The empirical and theoretical implications of this study were outlined in Chapter Two. Themes that emerged during data analysis were compared and contrasted with the theory and literature in Chapter Two.

Empirical Implications

Caregiver resources, interventions, and social maturation were all reflected in the empirical data included in the literature review. The results of this study may add contextual variables to the published literature about social skill development in people who have autism.

Caregiver resources encompassed financial, material, training, and human resources. Those resources were used for the physical and emotional wellbeing of the caregivers themselves, as well as providing necessities and comforts for the teenagers' and young adults' daily lives. Necessities and comforts included their basic needs of shelter, clothing, food, and someone who could be with them when their primary caregivers needed to be elsewhere. Other resources provided for their education or habilitation intervention and medical treatment. Interventions that had been provided in the public high school were not known by either Timothy's mother or grandmother. They just knew that he received interventions. This was an in-situ example of decreased caregiver involvement as children move into higher grades (Hirano et al., 2018a; Hirano et al., 2018b; Kurth et al., 2019; Rossetti et al., 2020; Scanlon et al., 2018). While academic and social interventions exist, autism necessitates individualization for those interventions to be successful (Barbieru, 2016; Kikas et al., 2016; Saint-Georges et al., 2020; Tanet et al., 2020; Trussell et al., 2018). Whether limited opportunities for adequate education are due to diminished resources, inadequate training, or a worldwide pandemic that demands social distance, the persistent academic and social needs of children with autism remain (Green-Hennessey & Mariotti, 2021; Neuman & Oz, 2021). The interventions that Timothy received, whatever they were, had little chance of being generalized into his daily life since his family was unable to explain what had been done to help him. This is not to say that the parents or the school personnel were neglectful. Decreased communication between home and school had become a common occurrence in both general education and special education as children moved into higher grades, affecting an ever-widening chasm of roles and perspectives between caregivers at home and school personnel (Hirano et al., 2018a; Hirano et al., 2018b; Kurth et al., 2019; Rossetti et al., 2020; Scanlon et al., 2018). This widening chasm may have had a negative effect on students who were transitioning from high school to their community.

Homeschooling families and caregivers were likely to measure academic achievement by skill level instead of yearly grade advancement, thereby granting credit for learning rather than time spent at a desk (Bishop et al., 2000; Gaither, 2009; Green-Hennessy & Mariotti, 2021; Neuman & Oz, 2021). Oliver's homeschool program was described differently than Levi's homeschool program, which was different than Zane's, yet the essentials remained. A specific hallmark of success in their programs was likely due to the division of roles across different adults in the student's life. The more family members, paid providers, and neighbors were involved, the less stress and strain the primary caregivers reported. Homeschooling allowed each of them and their caregivers the flexibility to deal with each person's physical and emotional needs while incorporating their interests, responsibilities, and appointments. Social skills and academics could be practiced while attending a dental appointment or as they picked up groceries for dinner. Life could be more integrated – responsibilities, reading, writing, math, and social skills.

Social maturation was described differently for each caregiver's charge. For the non-verbal young adults with autism, there was a strong desire to *Go? There's going?* which overrode other needs and wants, as evidenced by whenever there was any mention of going by their caregivers (even across the house), their other caregivers noted that their attention was drawn immediately and directly to *going* and getting by the door or into the vehicle. Even though Timothy could drive himself around town, he needed a ride when they went to the city. He, like every other teenager and young adult discussed, enjoyed going for a ride in the car.

Besides exhibiting more interest in going places and seeing people, social maturation was revealed in improved social skills, such as problem-solving, perspective-taking, prediction, and even purposeful deception are best learned in a child's natural environment since research shows that children with autism learn new things best when environmental factors are consistent (Welsh et al., 2019). Problem-solving skills are necessary to provide a foundation for higher cognitive functions, which include non-verbal skills for social interactions (Constable et al., 2018; Welsh et al., 2019).

Theoretical Implications

Although there are some exceptions, students with autism do not typically seek out social interactions in person or through social media (Simpson et al., 2017). Instead, they may be voracious consumers of unidirectional media, such as movies, television shows, and playing video games; persons with ASD often exhibit problematic behaviors and abnormal attachment when using video games (Aguillon-Hernandez et al., 2020; Simpson et al., 2017). Interventions that build on a child's interest by introducing social or academic activities to increase understanding would be an example of MKOs using scaffolding within the ZPD (Escolano-Perez et al., 2019; Lee et al., 2020; Mooney, 2013; Vygotsky, 1978).

Vygotsky's theory of Social Constructivism (1978) posits that knowledge and skills are acquired individually through interactions with MKOs in natural environments using a scaffolded approach . In the case of social skill development among children, teenagers, and adults with autism, this theory continued to reappear at every level. In every case and as reported by every caregiver, MKOs were vital to their student's acquisition of each element of social interaction. The MKOs reported were both themselves and other individuals that played a close, personal role in their student's life. Caregivers also cited MKOs for themselves, whose valuable knowledge, experience, or insight helped them and continued to help them care for their own needs, as well as the needs of their student.

Vygotsky's social constructivism advocated for the individual learning from the masses, or more knowledgeable others, rather than the masses learning from an individual (Vygotsky, 1978). This part of Vygotsky's theory lined up perfectly with the homeschooling experiences of the students in this study. Throughout the homeschooling experiences of Oliver, Levi, and Zane, MKOs who actively worked with them on academics changed, but those MKOs did not exit their lives. They were family members and neighbors who continued to influence them and interact with them beyond their time as their *teacher*. Those relationships continued at home, at family gatherings, and throughout the community, offering MKOs who had deep, personal interests in them as individuals and who made pointed efforts to communicate with them in ways they were able and comfortable.

As reported by their caregivers, none of these students could learn in a regular public-school classroom. The physical environment was either too distracting because of the lights, noise, and constant movement that overwhelmed the student with autism, or it was too restrictive to the internal noise and the need for constant movement of the student with autism. When these students were taught in the public-school, they were either too disruptive to the teacher and other students to facilitate their learning or the learning of those around them, or they cognitively abandoned the classroom by submersing themselves in self-stimulating behaviors, which also had the effect of being a disruption to those around them.

When Timothy was eventually identified as needing special services in high school, he was under the guardianship and custody of his parents. His grandmother had not been involved in his schooling, so she did not know what services he had received or what progress he had made. She did know that he was finally referred to special education when he was in tenth grade, but what was the cost of those lost years? How could his attitude toward learning and toward himself been affected in positive ways?

At the time of this study, he lived with his aged grandmother, needed continual reminders to take a bath and go to bed, and refused to participate in reading or writing activities because, “he says, ‘I’m not going to school anymore. I’m not going to school. I’m not going to do that.’” Considering the gains he had made since moving in with his grandmother at age 22, Timothy might have developed sufficient knowledge and skills to live as an independent adult had he had the opportunity for earlier interventions or to be homeschooled by MKOs in his natural environment. If an MKO had worked with him individually, perhaps those concepts he did not understand could have been addressed immediately. Perhaps he would not be so averse to improving his reading and writing skills. Perhaps his self-care and communication skills would have been more conducive to positive social interactions before he was 25. Thanks to his grandmother’s efforts, he had a way to remind himself to take a bath, was learning life skills by helping her around the house, was learning responsibility by feeding their animals, he passed the tests for his driver’s license, had his own vehicle, and was gainfully employed.

School environments are often considered natural environments during childhood, yet public school abruptly ceases to be a natural environment up on transition when a student leaves school or reaches the age of 22 and is no longer eligible to attend. Transitioning out of a public school necessitates adequate social skill development for interpersonal interactions and self-advocacy, which is required to continue to receive services during adulthood (Movahedazarhouligh, 2021; O’Brien et al., 2019; Odom et al., 2021; Welsh et al., 2019). Utilizing the social spheres model alongside an effective homeschool regimen, including various MKOs, might ease this transition into adulthood. Teenagers and young adults who can effectively and appropriately advocate for their needs in their homes and with other familiar adults are better prepared to advocate for them with other adults, organizations, and agencies in the wider world. Elements of social constructivism were present throughout all three themes that emerged in this study.

Limitations and Delimitations

My rationale for conducting a study based on teenagers with diagnoses of autism who were homeschooled in the rural Southwest United States was to identify social skill interventions that worked for each teenager and to explore caregivers' thinking about preparing their teens for transition into their community. If methods and practices could be successful for a family with few externally available resources, those methods and practices might have a higher likelihood of working for families in any location. Limitations were weaknesses of the study that could not be controlled. Delimitations were purposeful decisions the researcher made to limit or define the study's boundaries. I encountered more limitations than initially expected – some of those limitations were due to the delimitations I placed on the study.

Limitations

Limitations to this study included geographical location, changing activities of potential participants and their students, unstable internet connections, and participants who refused to participate. I anticipated limitations based on geographical location - there were only so many teenagers who were diagnosed with autism who were homeschooled in the area. I had misunderstandings with a previous dissertation chair, which cost over a year's time. During that time, some homeschooled teenagers moved out of the area, began attending public school, or turned 22. Unstable internet connections are common; one interview was dropped three times before we concluded. I was surprised by one potential participant who refused to participate – the timing of the interviews coincided with some major events in her life.

Delimitations

I delimited this study to explore the perspectives and experiences of caregivers over the age of 18 who worked with teenagers with a diagnosis of autism and were homeschooled in the rural Southwest United States. I used a hermeneutic phenomenological framework because I am a home and community-based speech-language pathologist and understood that I would not interpret the data with a transcendental mindset but rather from an interventionist point of view. These parameters included several delimitations; however, there were gaps in the literature for each. The goal was to identify social skill interventions that worked for each teenager and to explore caregivers' thinking about preparing their teens for transition into their community. If methods and practices could be successful for a family with few externally available resources, those methods and practices might have a higher likelihood of working for families in any location.

After the initial set of six interviews, my committee chair informed me that Liberty University had a policy of requiring a minimum of 10 participants for qualitative studies. Since I had already reached saturation within the stated parameters, it became necessary to expand those parameters to include caregivers of young adults who had a diagnosis of autism. The expansion yielded post-transition information and included nonverbal young adults, which ended up (in my opinion) adding richness to the data. Since I had to include additional participants after conducting the initial focus group interview, there ended up being three different focus groups.

Recommendations for Future Research

Considering the study's findings, limitations, and delimitations placed on the study, future research topics might include how the social skills of young adults affect employment opportunities within their communities; how different states or communities address assisted living for young adults and adults with autism; how sharing responsibilities as caregivers can be better for the caregiver and the teenager or young adults; and how the ‘parents as paid providers’ programs have affected parent roles and expectations. Teenagers and young adults with autism were included in the literature, but it was still lacking in quantity. Aside from the mental health factors, if the prevalence rate continues to rise as it has over previous years, the current assistance programs may become fatally overtaxed. As a preemptive effort, it might be better to seek ways to help this population attain gainful employment so they can be more independent.

Conclusion

As the prevalence of autism continues to rise, so must efforts to find ways to alleviate the symptoms of the individual and the negative impact on society. Social skills are a defining symptom of ASD, one which can result in lifelong dependency and mental or emotional disabilities. For individuals who have mild to moderate forms of ASD and who learn skills that facilitate appropriate social interactions, the general population may not know they have autism. Accessing trained, professional services to address the needs of children, teenagers, and adults in all geographical locations is not feasible. Trained professionals in autism can be difficult to find, but it is reasonable to expect that they would be easier to find in urban and suburban locations long before they might be found in rural locations. Autism, however, knows no boundaries. Homeschooling may be a way to reduce the cognitive and sensory overload that children who have autism battle. Even if homeschooling is not the perfect fit for every family, the features it offers might be what students with autism need so they can learn individualization in the form of an environment that is conducive to that student’s learning, personalized learning that incorporates their interests and moves forward only when they have attained understanding of the concepts being taught, increased caregiver awareness of struggles and achievements, and *teachers* who are constants in the student's life. By keeping their true natural environment constant, they may have better success at learning functional communication and self-regulation skills, which are foundational to learning social skills. Social skills, in turn, are foundational to successful integration into communities and workplaces, which research has shown to help alleviate comorbidities of depression and mental illnesses.

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Appendix A

LIBERTY UNIVERSITY.
INSTITUTIONAL REVIEW BOARD

December 28, 2023

Sondra Bistline
Janet Deck

Re: IRB Exemption - IRB-FY23-24-722 SOCIAL SKILL DEVELOPMENT IN TEENAGERS WITH AUTISM WHO ARE HOMESCHOOLED IN RURAL SOUTHWEST: A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCE OF CAREGIVERS

Dear Sondra Bistline, Janet Deck,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:
Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or

For a PDF of your exemption letter, click on your study number in the My Studies card on your Cayuse dashboard. Next, click the Submissions bar beside the Study Details bar on the Study details page. Finally, click Initial under Submission Type and choose the Letters tab toward the bottom of the Submission Details page. Your information sheet and final versions of your study documents can also be found on the same page under the Attachments tab.

Please note that this exemption only applies to your current research application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued exemption status. You may report these changes by completing a modification submission through your Cayuse IRB account.

If you have any questions about this exemption or need assistance in determining whether possible modifications to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,
G. Michele Baker, PhD, CIP
Administrative Chair
Research Ethics Office

Appendix B

Trustworthiness Section

Lincoln and Guba proposed qualitative terms that established the trustworthiness of a study in 1985 (Creswell & Poth, 2018). These terms are synonymous with terms traditionally used in quantitative research but better reflect the goals of qualitative research (Creswell & Poth, 2018). These qualitative concepts and terms include credibility, transferability, dependability, and confirmability (Creswell & Poth, 2018; Shenton, 2004). This section describes the measures I will take to ensure the quality and rigor of this qualitative study.

Credibility

Credibility, synonymous with internal validity, refers to how the findings measure or test a study's intended purpose and accurately reflect the participants' perception of reality (Creswell & Poth, 2018; Lincoln & Guba, 1985; Shenton, 2004). The higher the study's credibility, the more accurately the findings can be generalized across similar populations (Shenton, 2004). Techniques that I will use to achieve credibility include the development of an early familiarity with the culture of participating groups, triangulation of data collection, peer scrutiny and review, and member checks.

Development of an Early Familiarity with the Culture

Cultural familiarity influences professional judgments and will be checked by peer scrutiny and member checks. Visits to local community events, homes, homeschools, and micro-schools within the target communities have assisted my familiarity with the investigated cultures. Interactions between myself and community members have improved trust and should improve their willingness to participate and speak frankly during interviews (Shenton, 2004).

Triangulation

In this study, I will use three data collection methods to triangulate the collected information, sources of information, and theories that emerge in the data. By employing triangulation, I seek to gain insights into the background information to inform levels of social skill development in support of, or that contrasts with, the current perspectives of the participants (Shenton, 2004). The data collection methods that I will use to fulfill triangulation include caregiver responses to journal prompts, individual interviews of parents and other caregivers of teenage students who have ASD and attend homeschool or micro-schools in their community, and a focus group consisting of the parents and caregivers who have been interviewed individually.

Peer Debriefing

Peer debriefing and scrutiny of the research project by colleagues and peers will ensure a comprehensive perspective and a focus on the topic of investigation. Feedback will be welcomed to check that my opinions, beliefs, and attitudes do not obscure the participants' perspectives or experiences while keeping the purpose of the study at the forefront (Shenton, 2004). Challenges to my assumptions could improve my objectivity and the credibility of the study.

Member Checks

Member checks will ensure the accuracy of the recorded interview transcripts and my theories or inferences based on the interviews and the resulting transcriptions. After transcribing the interviews and before data analysis begins, the participants will be asked to read their interview transcripts to verify the accuracy of the recorded information. A second member check could verify that my emerging theories and inferences agree with their experiences. Members may be asked to offer reasons for patterns that I may observe. Accuracy of data is essential for correctly representing each participant's life experiences concerning theories and for the overall credibility of the study (Shenton, 2004; van Manen, 1997).

Transferability

Transferability is a measure of the extent to which the findings of a research study can be applied to other settings and populations (Lincoln & Guba, 1985; Shenton, 2004; van Manen, 1997). For this study, I will seek to enhance the transferability of the findings for the social skill development of other teenage students with autism who live in other communities and in different circumstances. Variables of the specific contexts studied may be important to transferability to contexts sought by potential future readers of the completed study. The variables for this proposed study will be elucidated using thick descriptions when presenting the research findings to illustrate how the students' social skill development impacts their functional interactions with adults, children, and peers within their community (Shenton, 2004).

Dependability

Dependability shows that the findings are consistent and could be repeated (Lincoln & Guba, 1985). Descriptions of my procedures will be comprehensive so that this study could be replicated with other populations and in other geographical regions. Overlapping methods of journal prompt responses, individual interviews, and focus group interviews will provide the opportunity to increase dependability. Dependability is accomplished through an inquiry audit, which will occur at Liberty University during a thorough review of the research process and the research products by the dissertation committee and the Qualitative Research Director.

Confirmability

Confirmability is a degree of neutrality or the extent to which the respondents shape the findings of a study instead of researcher bias, motivation, or interest (Lincoln & Guba, 1985).

Although researcher bias is unavoidable, instrumentation can decrease dependence on human skill and perception (Shenton, 2004). To ensure the confirmability of this study, to the greatest extent possible, I will use triangulation, audit trails, and reflexive commentary as three different techniques to establish confirmability (Shenton, 2004). Triangulation will be used to develop a comprehensive understanding of the phenomena and to reduce the effect of investigator bias (Shenton, 2004). Audit trail diagrams will illustrate the course of decision-making throughout the research process (Shenton, 2004). Reflexive commentary will be employed through memos, compiled into a journal to bracket my biases as the researcher investigator and inform the audit trail (Shenton, 2004).

Appendix C

Theoretical Context Section from Chapter One

In the 1930s, theorists who worked primarily in child psychiatry most closely associated some descriptions of schizophrenia with intelligent, distant parents who were cold in their interactions with their children, leading to the use of the destructive term "refrigerator mother" in the late 1960s which still impacts attitudes and opinions today (Bettelheim, 1968; Blacher & Christensen, 2011; Despert, 1938, 1952, 1968; Evans, 2013; Fellowes, 2015; Kanner, 1943; Sterwald et al., 2019). Theories associated with emotionally distant parents were used to frame treatment, which alternatively evolved and devolved. Treatment began as primarily institution-based, adult-led, and adult-reinforced peer interactions that included prompting, direct teaching techniques, and positive reinforcement, along with mixed results from applied behavioral analysis given the use of aversive procedures (Allen et al., 1964; Kirby & Toler, 1970; Lovaas, 1971; Lovaas, 1987). In the 1970s, social interventionist research began to focus on reciprocal social interactions instead of individual social behaviors, active involvement of parents in their children's learning and development, incorporation of peer-mediated reciprocal social interactions, and recognition that challenging behaviors could be a form of communication (Gaylord-Ross et al., 1984; Iwata et al., 1994; Odom & Strain, 1986; Schopler & Reichler, 1971; Strain & Shores, 1977; Strain et al., 1978). When aversive behavior management techniques were proven harmful in 1988, the psychiatric community was divided, but by 1997, the United States federal government issued the Individuals with Disabilities Education Act that, for the first time, mandated functional behavior assessments before developing a behavior plan and required consideration of positive behavior interventions to support students (Berkman & Meyer, 1988; Odom et al., 2021; U.S. Department of Education, 2022).

The interventions which began to be implemented in the 1970s were primarily informed and supported by the social constructivist theory as a collaborator or more knowledgeable other (MKO) took the form of a child's parent or peer during reciprocal social interactions (Epstein, 2011; Mooney, 2013; Odom & Strain, 1986; Vygotsky, 1978). Parents and peers are ideal MKOs because they share values, beliefs, language, and problem-solving skills with which the child would be most familiar (Odom & Strain, 1986; Strain & Shores, 1977; Strain et al., 1978; Vygotsky, 1978). The shared values, beliefs, language, and problem-solving skills would be familiar to children with ASD and provide a framework to learn socially appropriate behaviors within their own cultural experiences as they progress within their Zone of Proximal Development (Vygotsky, 1978). Given appropriate training and coaching by professionals, parents, and peers would be in an ideal position to support and reinforce, through scaffolding, the daily development of knowledge, skills, and abilities (Mooney, 2013; Odom & Strain, 1986; Strain & Shores, 1977; Strain et al., 1978; Vygotsky, 1978).

Appendix D

Research Questions

Phenomenological Research Questions:

Central Research Question

What are the caregivers' lived experiences of social interactions with their homeschooled teenagers diagnosed with autism?

Sub-Question One

How do caregivers describe their students' social interactions at home?

Sub-Question Two

How do caregivers describe their students' social interactions in community settings?

Sub-Question Three

As a more knowledgeable other (MKO) in your student's life, how do caregivers ensure their student reaches an appropriate zone of proximal development (ZPD) to live as independently as possible?

Appendix E

Journal Prompt

Journal Writing Prompts

Prompt #1. Describe your journey as a caregiver of a teenager/young adult with autism.

Prompt #2. What would you like your community to know about your teenager/young adult with autism?

Appendix F

Sample Journal Prompt Response

Journal Prompt #1

As far back as I can remember, I've had a real special love and care in my heart for people with autism, as well as all special needs people. Two of my brothers – [redacted], who's 4 years younger and [redacted], who's 9 years younger than me – we diagnosed with autism, each at about age 2, so that's always been a big part of my life. Father always told us they were special spirits in Heaven and very sensitive to the attitudes of people around them, and I bear testimony, it's true. When I was 16, I started helping at CC, a special needs school that my brothers attended, and helped there for several years.

When I was 24-25, I lived far away and didn't get to help [redacted] and [redacted] at all, so when I moved back next door to them, I was more interested than ever in helping them. In 2015, I became certified as a respite provider, and in 2017, as an attendant care provider, and totally loved my job taking [redacted] and [redacted] for rides, cleaning their rooms, making food for them, doing coloring and other activities with them, and best of all, just talking to them and being their friend.

Neither of the boys have ever spoken clearly, but living with them and near them so long, I've come to understand the meaning of "atu baboo" (happy smile) and lots of other amazing words. In 2018, [redacted] was killed when he climbed into a substation, not understanding the danger, and was electrocuted. We miss him very much, and I feel like [redacted] does most of all – those boys were very close, and I know that one day, they'll meet again in Heaven and I want to live so I can, too. Since that time, the other providers have quit and I've been the sole respite and attendant care provider for [redacted] – still love my job!

People tell me sometimes that he only likes talking to me and I just smile – that comes from years of on-purpose being kind to him and repeating, "we're happy, we smile, we eat food," many hundreds of times over. Just like any of us, when we find someone who likes to listen to and talk to us, and aren't too busy for us, then we know we have a friend. That is how [redacted] is too.

Journal Prompt #2

So, first of all, with [redacted] and other people with autism or other special needs, especially those who can't talk clearly – please, everyone, think of them and treat them as people – real, live, human people with hearts that beat and minds that think – because they are!

Please don't ignore them or talk down to them – they like smiles and cheerful, normal, mature greetings just as much as others do.

If ever you see someone wandering the street who acts like they're off in their own world and don't reply when you talk to them, please call for help to get them home. They often love to wander and they don't realize the danger of traffic, substations, water, heights, creepy people, etc. They need our help to keep them safe.

Always speak calmly and clearly and keep your spirit calm – they react very much according to the spirit of those around them and if someone yells, there goes all control. Those of us who've been diagnosed as society's norm are responsible to keep the peace around them. Just like anyone else, they'll get scared if you surprise them by coming from the back, on a blind

Appendix G

Individual Interview Questions

1. When did you begin your role of caregiving with your student? (age) CRQ
2. Describe early interactions between you and your student. CRQ
3. Describe social interactions you observed before your student and other people. CRQ
4. How does homeschooling fit into your life? CRQ
5. What influenced the decision to homeschool or micro-school? CRQ
6. What do you think is the most positive aspect of homeschooling/micro-schooling? CRQ
7. What has been the most difficult part of homeschooling/micro-schooling? CRQ
8. What challenges do you face when homeschooling/micro-schooling because of your rural location? CRQ
9. Tell me about interventions used to address communication or the development of social skills. SQ2
10. Describe how you feel homeschooling/micro-schooling has affected social skill development for your student with autism. SQ2
11. Describe social interactions at home. SQ1
12. Describe social interactions in the community. SQ1
13. What do community outings look like? (*may use prompts like the grocery store, Walmart, park, post office) SQ1
14. What activities do you share? (Such as joining, stimming) CRQ/SQ2
15. What behaviors do you see in your student that reflect your interactions? SQ2
16. When you are not acting as caregiver, who do you spend time with? CRQ
17. Are there any groups you spend time with? CRQ

18. As a homeschool parent of a child with autism, who do you consider a model or mentor for yourself? CRQ
19. How do you envision life will look for (teenager with autism) when they are an adult? (*may use prompts like college, trade tech, employment, independent living) SQ3
20. Describe challenges you face because of your rural location. CRQ
21. Describe the benefits of living in a rural location. CRQ
22. What else would you like to add to our discussion of your experiences with homeschooling a teenage student with autism? CRQ

Appendix H

Sample Transcript of Individual Interviews

[redacted] 04:18

So with homeschooling for me personally or with him? As far as making it work with me, we're able to work either over zoom or one-on-one, face-to-face. We're able to focus more on the things that he's interested in and the things that he can understand. As well as, um, trying to not…try to create more of a learning environment. So having that one-on-one academics makes it a lot more...what's the word I'm looking for... customizable.

[redacted] 05:14
Perfect, and what influenced the decision to homeschool?

[redacted] 05:29
The decision was kind of made through the [redacted] program's principle of the best place to

learn is at home with less stimulation.

[redacted] 05:39
Perfect okay. What do you think is the most positive aspect of homeschooling for him?

[redacted] 05:49
I think the most positive aspect for him is the low stimulation.

[redacted] 05:58
And what's been the most difficult part?

[redacted] 06:02

Probably getting him to do things that he doesn't really want to do. So doing the more difficult tasks of teaching. If he doesn't want to, it's like Okay, walk away and we have a hard time sometimes focusing on things that were not interested in. If that makes sense.

[redacted] 06:29

Oh, it does. I have the same experience with him, even though we're not homeschooling. Can you describe any special education services that have been used to meet his needs?

[redacted] 06:48

Um, to meet his needs? Yes, we have done special rooms for him. We have done computers, laptops, things like that to encourage the learning environment as well as like his own desk, comfortable chair, drawing board or whiteboards different resources to show him... books, like educational books as well as educational websites. There's also skills training so plants, and things like that... dirt, soil... We've also done walking shoes for exercising and we've also done I think, we've also been able to do like Legos... things like that were incentives for a while trains...

[redacted] 07:47
Okay. So tell me about the interventions that you've used to address communication or the

development of social skills.

[redacted] 07:56
Intervention, help me remember, just for a second, what that entails.

[redacted] 08:01

Appendix I

Focus Group Questions

1. What is it like being a caregiver of someone diagnosed with autism? CRQ
2. How does autism affect your home life? CRQ
3. How do people react to your teenagers' behaviors when in public? SQ2
4. What would you like the public to know about how it is to live and work with someone who has autism? SQ2
5. Describe your ideal vision about how your teenager will transition to adult life. SQ3

Appendix J

Sample Transcript of Focus Group Interviews

[redacted] 21:37

Yeah, I just like him to be able to be, you know, as independent and successful as, you know...it... like [redacted] said, as anybody else you know? He'll be able to live on his own and not in a group home. Be able to learn, learn essential skills, be able to enter the workforce, be able to eventually get married and have a family, you know, of his own. Uh, If he wants to do that. Definitely he wants to get married - I know that. And just seeing him just kind of coming to us, you know for help and support but not depending on us. So, basically independence and good decision-making.

[redacted] 22:29

Wonderful, thank you. All right, [redacted] are you in a good spot?

[redacted] 22:34
Yeah, I'm in a good spot finally. Sorry about that. Will you repeat that question for me?

[redacted] 22:39
Yes. So, describe your ideal vision about how your teenager will transition to adult life.

[redacted] 22:44

So [redacted] is 16 going on 17 and he's about probably a nine year old I would guess, in his mind and stuff. I mean, in in what he can do in his mind, he's definitely a 16 year old and I need to not call him a teenager. He's a young adult. I think as far as transitioning in his life and the world around him, I think the biggest thing is finding out what his needs are right now so that he can do that transitioning... and moving him step-by-step towards that. And then the transition in is what is what he wants to do? Like helping him find his dreams and hopes and that kind of thing. But then also like [redacted] brought up I think having a place for them is super important. And [redacted] and I have talked a lot about, with you even, like [redacted] and having a place where it's actually a little individual living for them. So they can feel like they're part of a little community, a little group but not exclusive from anyone else. But still, it would be nice for [redacted] to be able to have kind of that kind of a setting where I have some independence to living. As far as seeing [redacted] get married and that kind of thing. I have no idea what the future will hold [redacted] come so much further than I ever even anticipated him coming. But I can't say NO to anything anymore. Because I you know, I played a little map block game with him the other day and I got 400 and he got 1600. So it's like, how do I know what this kid's potential is? You know, so there's just there's that and I think being open as parents and keeping our minds open to what they may transition into is just as important as "what is the world going to accept them as?" and how that kind of stuff. I think it's what do we accept them as and how much are we willing to let them grow and change and become who they eventually want to be? I don't think they have an idea in their head of exactly who they want to be any more than say we did at their age but - but yeah, as far as that I just feel like we as parents have to put things in place so that their life can be a little bit easier. But we have to also be realistic. They may never get married. What if they don't get married? What have we done to put things in place for that kind of thing. So I don't know if that helped very much.

[redacted] 23:29
That's great. Thank you. So [redacted] joined us, [redacted] Do you want to take a swing at this one? So it's describe your ideal vision about how your teenager will transition to adult life.

[redacted] 25:36

So, the ideal situation would be that he would be functioning enough to take care of his own finances, living condition, and ask for help, if needed or able to set in place the help that's required. And then, probably the alertness. Be alert of situations people - be able to read what you know, what's being said how it's being said, that kind of thing. Basically, the needs that you try to teach children, regardless, in order to function as adults. So "do you know how to make sure your place is nice and clean? Do you know how to make your food do you know how to work manage your money?" Or "do you know how to understand if people are safe? Not safe?" That kind of thing.

[redacted] 26:33

Appendix K

Research Permission Email

<Today's Date>

<Board of Director Name>
Director of the Board
<Name of Organization>
<Address>
<City, State, Zip>

Dear <Director's Name>,

As a graduate student in the School of Education at Liberty University, I am conducting research as part of the requirements for my doctoral degree in Education: Special Education. The title of my research project is Social Skill Development in Teenagers with Autism Who are Homeschooled in Rural America: A Phenomenological Study of the Lived Experience of Caregivers, and the purpose of my research is to explore the perceptions of caregivers regarding social skill development in teenaged students diagnosed with Autism who live in this rural region of the Southwestern United States.

I am writing to request your permission to contact members of your organization to invite them to participate in my research study. Participants will be presented with informed consent and assent information prior to participating. Participation in this study is completely voluntary, and participants are welcome to discontinue participation at any time.

Thank you for considering my request. If you choose to grant permission, respond by email to [redacted]. A permission letter document is attached for your convenience.

Sincerely,

Sondra J. Bistline, MS, CCC-SLP, ATP
Doctoral Candidate

Appendix L

Site Permission Response Form

<Date to be entered by Respondent>

[redacted]

Dear Ms. Bistline:

After carefully reviewing your research proposal entitled Social Skill Development in Teenagers with Autism Who are Homeschooled in Rural America: A Phenomenological Study of the Lived Experience of Caregivers, I have decided to permit you to contact our members/parents/families to invite them to participate in your study.

Check the following boxes, as applicable:

☐ We grant permission for Sondra J. Bistline to contact members, parents, and families to invite them to participate in this research study.

☐ The requested data WILL BE STRIPPED of all identifying information before it is provided to the researcher.

☐ The requested data WILL NOT BE STRIPPED of identifying information before it is provided to the researcher.

☐ We request a copy of the results upon study completion and/or publication.

Sincerely,

<Official's Name>
<Official's Title>
<Official's Company/Organization>

[redacted]

June 5, 2023

[redacted]

Dear Ms. Bistline:

After carefully reviewing your research proposal entitled Social Skill Development in Teenagers with Autism Who are Homeschooled in Rural America: A Phenomenological Study of the Lived Experience of Caregivers, I have decided to permit you to contact our members/parents/families to invite them to participate in your study.

Check the following boxes, as applicable:

☐ We grant permission for Sondra J. Bistline to contact members, parents, and families to invite them to participate in this research study.

☐ The requested data WILL BE STRIPPED of all identifying information before it is provided to the researcher.

☐ The requested data WILL NOT BE STRIPPED of identifying information before it is provided to the researcher.

☐ We request a copy of the results upon study completion and/or publication.

Sincerely,

[redacted]

[redacted]

June 6, 2023

[redacted]

Dear Ms. Bistline:

After carefully reviewing your research proposal entitled Social Skill Development in Teenagers with Autism Who are Homeschooled in Rural Arizona: A Phenomenological Study of the Lived Experience of Caregivers, I have decided to share your flyer regarding the study with our families and members.

Check the following boxes, as applicable:

☐ We grant permission for Sondra J. Bistline to contact members, parents, and families to invite them to participate in this research study.

☐ The requested data WILL BE STRIPPED of all identifying information before it is provided to the researcher.

☐ The requested data WILL NOT BE STRIPPED of identifying information before it is provided to the researcher.

☐ We request a copy of the results upon study completion and/or publication.

Sincerely,

[redacted]

[redacted]

6/15/2023

[redacted]

Dear Ms. Bistline:

After carefully reviewing your research proposal entitled Social Skill Development in Teenagers with Autism Who are Homeschooled in Rural Arizona: A Phenomenological Study of the Lived Experience of Caregivers, I have decided to share your flyer, regarding the study that you are doing, with our families and members. This way our members/parents/families may reach out to you if they are interested in participating in your study.

Check the following boxes, as applicable:

We grant permission for Sondra J. Bistline to provide the Foundation with a flyer that we will share with our parents, and families. The flyer will invite our members to participate in this research study.

X The requested data WILL BE STRIPPED of all identifying information before it is provided to the researcher.

The requested data WILL NOT BE STRIPPED of identifying information before it is provided to the researcher.

X We request a copy of the results upon study completion and/or publication.

Sincerely,

[redacted]

Appendix M

Recruitment Letter/Email

[Date]

[Recipient]
[Title]
[Company]
[Address 1]
[Address 2]
[Address 3]

The date and recipient address information included above is for recruitment letters that I will mail to potential participants. I will remove it if I plan to email my recruitment information.

Dear [Recipient]:

As a graduate student in the School of Education at Liberty University, I am conducting research as part of the requirements for a Doctoral degree in Special Education. The purpose of my research is to describe the lived experiences of adult parents and caregivers of social skill development for teenage students with autism in the rural Southwest, and I am writing to invite eligible participants to join my study.

Participants must be:

- 18 years or older, and
- provide services to a student who is homeschooled and diagnosed with autism for ten or more hours per week.

Participants, if willing, will be asked to:

ACTIVITY	ESTIMATED TIME
• respond to a journal prompt	10-30 minutes
• Individual Interview (videoconference or in-person)	30 minutes
• Focus Group (videoconference or in-person)	45-60 minutes
• Review transcripts of interview and focus group to verify accuracy	30 minutes

Names and other identifying information will be requested as part of this study, but the information will remain confidential.

To participate, please complete the attached survey and return it by either handing it to me personally or placing it in the provided envelope and returning it by mail. Contact me at [redacted] or [redacted] for more information or to schedule an interview.

A consent document is provided on the first page of the survey. The survey will be on the second page, and a journal prompt will be on the third page. Please return the consent document, demographic survey, and journal entry to me before our interview. You can return the documents by mail in the addressed, stamped envelope provided, give them to me in person, or scan the documents and return them by email [redacted]. The consent document contains additional information about my research.

Sincerely,

Sondra J. Bistline
Doctoral Candidate
[redacted]
[redacted]

Appendix N

Recruitment Verbal

Hello [Potential Participant],

As a graduate student in the School of Education at Liberty University, I am conducting research as part of the requirements for a Doctoral degree in Special Education. The purpose of my research is to describe the lived experiences of adult parents and caregivers of social skill development for teenage students with autism in the rural Southwest. If you meet my participant criteria and are interested, I would like to invite you to join my study.

Participants must be:

- 18 years or older, and
- provide services to a student who is homeschooled and diagnosed with autism for ten or more hours per week.

Participants, if willing, will be asked to:

ACTIVITY	ESTIMATED TIME
• respond to a journal prompt	10-30 minutes
• Individual Interview (videoconference or in-person)	30 minutes
• Focus Group (videoconference or in-person)	45-60 minutes
• Review transcripts of interview and focus group to verify accuracy	30 minutes

Names and other identifying information will be requested as part of this study, but the information will remain confidential.

Would you like to participate?
[Yes] Great,

- could I get your email address so I can email you the survey? would you complete this survey and return it by handing it to me or placing it in the provided envelope?
- can we set up a time for an interview?
- Are there others who are providers or caregivers for your child? Would you allow me to contact them as potential participants in this study?

[No] I understand. Thank you for your time. [Conclude the conversation.]

A consent document is provided on the first page of the survey. The survey will be on the second page, and a journal prompt will be on the third page. Please return the consent document, demographic survey, and journal entry to me before our interview. You can return the documents by mail in the addressed, stamped envelope provided, give them to me in person, or scan the documents and return them by email to [redacted] The consent document contains additional information about my research.

Thank you for your time. Do you have any questions?

Appendix O

Recruitment Follow Up Letter

Dear [Recipient],

As a graduate student in the School of Education at Liberty University, I am conducting research as part of the requirements for a Doctoral degree in Special Education. Last week, an email was sent to you inviting you to participate in a research study. This follow-up email is being sent to remind you to respond if you would like to participate and have not already done so. The deadline for participation is [Date].

Participants, if willing, will be asked to:

ACTIVITY	ESTIMATED TIME
• Demographic Survey	10 minutes
• Respond to a journal prompt	10-30 minutes
• Individual Interview (videoconference or in-person)	30-45 minutes
• Focus Group (videoconference or in-person)	45-60 minutes

Participants must be 18 years or older and regularly involved (10 or more hours per week) with a teenage or young adult student who is homeschooled or micro-schooled. Adults may be parents, foster parents, guardians, extended family members, teachers or guides, habilitation, or respite providers. Participation in this research is voluntary. Names and other identifying information will be requested as part of this study, but the information will remain confidential.

To participate, contact me at [redacted] or [redacted] for more information or to schedule an interview.

After eligibility is determined, a demographic survey and journal prompt will be emailed to you. You will return the demographic survey and journal entry to me before our interview. You can return the documents by mail in the addressed, stamped envelope provided, give them to me in person, or scan the documents and return them by email to [redacted] The information sheet contains additional information about my research but does not need to be signed and returned.

Sincerely,
Sondra J. Bistline
Doctoral Candidate

Appendix P

Information Sheet for Adult Participants

Title of the Project: SOCIAL SKILL DEVELOPMENT IN TEENAGERS WITH AUTISM WHO ARE HOMESCHOOLED IN RURAL SOUTHWEST: A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCE OF CAREGIVERS

Principal Investigator: Sondra J. Bistline, Doctoral Candidate, School of Education, Liberty University

Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be:

- 18 years or older
- Regularly involved (10 or more hours per week) with a teenage or young adult student who is homeschooled or micro-schooled in the capacity of:
    - Parent, Foster Parent, or Guardian
    - Extended Family Member (examples may include grandparents or adult siblings)
    - Teacher or guide
    - Habilitation or Respite Provider

Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about and why is it being done?

The purpose of the study is to describe caregivers' lived experience of social skill development for teenage students with autism in the rural Southwest.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

ACTIVITY		ESTIMATED TIME
1. Complete demographic data sheet and respond to a journal prompt	Write, type, or record your response to a journal prompt.	10-30 minutes
2. Individual Interview (videoconference or in-person)	Participate in an in-person or virtual interview. Interviews will be audio-recorded and video-recorded for transcription of the interview.	30-45 minutes

3. Focus Group (videoconference or in-person)	Participate in an in-person or virtual focus group. The focus group will be audio-recorded and video-recorded for transcription of the interview.	45-60 minutes
Overall Time Estimated for Total Participation		**2 – 2 ½ hours**

How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

Benefits to society include an increased awareness of practices that can positively affect the development of social skills for people diagnosed with Autism.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records.

- Participant responses will be kept confidential by replacing names with pseudonyms.
- Interviews will be conducted in a location where others will not easily overhear the conversation.
- Confidentiality cannot be guaranteed in focus group settings. While discouraged, other focus group members may share what was discussed with persons outside of the group.
- Data collected from you may be used in future research studies or shared with other researchers. If data collected from you is reused or shared, any information that could identify you will be removed beforehand.
- Data will be stored on a password-locked hard drive in a locked file cabinet. After three years, all electronic records will be deleted, and all hardcopy records will be shredded.
- Recordings will be stored on a password-locked hard drive in a locked file cabinet until participants have reviewed and confirmed the accuracy of the transcripts and then deleted. The researcher and members of her doctoral committee will have access to these recordings.

Is the researcher in a position of authority over participants, or does the researcher have a financial conflict of interest?

The researcher serves as a Speech-Language Pathologist at Speak'N Up!, LLC. This disclosure is made so you can decide if this relationship will affect your willingness to participate in this study. No action will be taken against an individual based on their decision to participate or not participate in this study.

Is study participation voluntary?

Participation in this study is voluntary. Your decision on whether to participate will not affect your current or future relations with Liberty University or the researcher. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you, apart from focus group data, will be destroyed immediately and will not be included in this study. Focus group data will not be destroyed, but your contributions to the focus group will not be included in the study if you choose to withdraw.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Sondra J. Bistline. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at [redacted] or [redacted] You may also contact the researcher's faculty sponsor, Janet Deck, at [redacted]

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Appendix Q

Demographic Data

Participant (Adult)

Name:	
Gender:	
Age Range: *(Circle one)*	18-30 31-40 41-50 51-60 61+
Relation to Student:	
Race / Ethnicity:	
Marital Status: *(Circle one)*	never married married separated divorced widowed plural other:
Education Level: *(Circle one)*	less than high school high school some college Technical certification college degree: ________

Student (Child)

Gender:	
Age:	
Current Grade Level *(if known)*:	
Place in Siblings *(first, second, third, etc)*:	
Age When Parent First Became Concerned about Child's Development:	
Age at Diagnosis:	
Maternal Age at Child's Birth:	
Paternal Age at Child's Birth:	
Maternal Education Level: *(Circle one)*	less than high school high school some college Technical certification college degree: ________
Paternal Education Level: *(Circle one)*	less than high school high school some college Technical certification college degree: ________

Household

Size of Household *(number of people living in home):*	
Household Income Range: *(circle one)*	$18,000 or less $18,001-$36,000 $36,001-$50,000 $50,001-$80,000 $80,001-$120,000 $120,000+

Appendix R

Emerging Interventions

Emerging interventions include Augmentative and Alternative Communication (AAC), Exercise and Movement (EXM), Functional Communication Training (FCT), Music-Mediated Interventions (MMI), and Technology-aided Instruction and Intervention (TAII). There is evidence that social skills groups, peer-mediated interventions, and technology-based interventions are effective for some students with autism (Bertilsdotter-Rosqvist, 2019; Brady et al., 2020). Studies that add to the body of literature to support these emerging intervention practices include the following:

1. Augmentative and Alternative Communication (AAC). Educational teams in the United States are "mandated to consider students' assistive technology needs during the process of developing individualized education programs (IEP) for students with disabilities" (Andzik et al., 2019; IDEA, 1997). AAC options include unaided and aided forms of communication. Unaided forms such as gestures, eye gaze, and sign language require specific training but do not require specific equipment beyond the person's body; aided AAC requires specific training for the user and other people who will need to assist the student with programming their AAC and promoting meaningful and effective communication with the student, along with specific tools or equipment such as pictures, communication boards, switches, and speech-generating devices (SGD) (Andzik et al., 2019). For students who are non-verbal, there is more availability and use of AAC. However, teachers, families, and community members may discourage AAC use due to cost, inconvenience, misbehavior, or lack of training (Andzik et al., 2019; Odom et al., 2021; White et al., 2021).

2. Exercise and Movement (EXM) will not be addressed as it is beyond the scope of this paper.
3. Functional Communication Training (FCT). FCT aims to replace challenging behavior with socially acceptable communication that achieves the child's purpose. Socially acceptable communication may be verbal, aided, or unaided AAC. FCT has obtained moderate evidence to support its use for children 0-8; its weakness seems to be that the behavior is quickly extinguished if not regularly reinforced (Alakhzami & Chitiyo, 2022; Muharib & Wood, 2018). More positive evidence was presented in a study of FCT with toddlers at risk for autism and problem behavior (Neely et al., 2022). Note: FCT was cited by one of three reviewed studies as evidence based. This statement contradicts the published NCAEP publication (NCAEP, 2020).
4. Inclusive Music Class. In the study, this setting provided peer-mediated intervention. It offered opportunities to engage with a social skills group in an inclusive music class providing familiar and repetitive experiences while offering novelty for learning to adapt while simultaneously engaging with peers (Lee & Chang, 2021). Other EBPs utilized in the music class include social stories, peer mediation, video modeling, and visual cueing strategies (Lee & Chang, 2021). Music technology can be implemented at any age and across various environments (Lee & Chang, 2021).
5. Technology-aided Instruction and Intervention (TAII). TAII can range from simple instruction for tasks to more involved interventions. Computer-assisted instruction (CAI), to develop and maintain on-task behavior during transitions, might use two-minute videos (video modeling), recorded verbal transition prompts (prompting), visual countdown clocks (prompting, self-management, visual supports), and music

during transitions (antecedent, response interruption & redirection, prompting, time delay) (Iovannone & Anderson, 2022). Emerging social intervention treatments include transcranial direct current stimulation (tDCS) and immersive virtual reality as educational tools. These emerging treatments have limited evidence at this time. Transcranial direct current stimulation (tDCS) is used to improve emotional recognition through facial expression in others by applying stimulation to the right temporoparietal junction (rTPJ) (Wilson et al., 2021). Transcranial direct current stimulation (tDCS) is a treatment that utilizes a visual framework and video feedback to recognize facial emotions that communicate threats or improve empathy (Wilson et al., 2021). Immersive virtual reality interventions for developing communication skills and problem-solving by people with autism show promise as an educational tool, which may indicate the positive effects of self-directed learning on technology-enabled teaching (Geng et al., 2019; Herrero & Lorenzo, 2020). Virtual reality and the utilization of technology for teaching social skills may have a basis for the abnormal pupil dilation of people who have autism. Separate studies conducted in the Slovak Republic and Spain were on the central autonomic regulation of pupil dilation in response to facial recognition and emotional-cognitive processing and comparing the responses of typically developing subjects with those of subjects who had autism (Aguillon-Hernandez et al., 2020; Ferencova et al., 2021). By measuring pupil dilation, researchers found that people with autism were insensitive to objects, static faces, and dynamic faces; however, pupil dilation indicated an emotional response to virtual faces (Aguillon-Hernandez et al., 2020; Ferencova et al., 2021).

Appendix S

Intervention Programs

There are several other evidence-based intervention programs for developing social skills. Two online evidence-based sites are free of charge (without credit) – one is geared toward school professionals, interventionists, and university students, and the other is professional-friendly but is geared toward student and parent education (https://afirm.fpg.unc.edu; https://autisminternetmodules.org). Still, families may be out of luck if they are not residents of the state where it is located unless they have access to a licensed and certified practitioner in the state where the patient lives (ESDM, PEERS®, PRT, RDI, TEACCH®).

AFIRM (Autism Focused Intervention Resources and Modules). AFIRM offers modules about Basic ABA and instructional or intervention strategies like antecedent-based interventions, reinforcement, prompting, and functional behavior assessment for children birth through 22 (https://afirm.fpg.unc.edu). AFIRM currently has 30 online modules for teachers, Speech-Language Pathologists, early interventionists, administrators, and university students. The modules are free once an account on their site has been established, but for a fee of $35.00 per module, professionals can obtain certificates of continuing education units (CEUs) (https://afirm.fpg.unc.edu).

AIMS (Autism Internet Modules). AIMS provides online modules that are between 30 minutes to 3 hours each, available to students, parents, interventionists, and teachers. The modules are free of charge once an account is established on their site (https://autisminternetmodules.org). Modules include information about interventions and topics, spanning ages of toddlers to adults with autism – including PRT training for which a certificate can be obtained for $30, a deal since neither in-person nor virtual training is available through the University of California – Santa Barbara's The Gevirtz School (UCSB) at this time (https://autisminternetmodules.org).

ESDM (Early Start Denver Model). The ESDM provides naturalistic developmental behavioral interventions (NDBI), using parent involvement and behavioral therapy for children with autism between 12 and 48 months of age (www.autismspeaks.org; https://www.esdm.co; Rogers & Dawson, 2010; Rogers & Dawson, 2012; Rogers & Dawson, 2021). Training is offered in multiple tiers: introductory, advanced, and parent coaching. Workshops may be online or in-person and are available to licensed Psychologists, BCBA practitioners, Occupational Therapists, Speech-Language Pathologists, Early Intervention Specialists, and Developmental Pediatricians. The cost is around $2100, plus travel expenses (varies by location) (https://www.esdm.co).

PEERS® (Program for the Education and Enrichment of Relational Skills). PEERS® provides treatment options that utilize social skills groups through 16-week online modules, which last 90 minutes each week, along with more intense boot camps. Their courses cover a broad swathe of topics for preschoolers, adolescents, and young adults, which include online social skills, careers, dating, conversation boot camps, dating boot camps, friendship boot camps, bull proofing boot camps, virtual boot camps, and a 5-week dating class (UCLA). Treatment is provided by trained and certified PEERS® providers who can be located on their database (www.semel.ucla.edu/peers). The price for treatment is an intake fee of $300 and a weekly fee of $100-$130. They offer certification training to mental health professionals, medical professionals, school-based professionals, Speech-Language Pathologists, Occupational Therapists, Recreational Therapists, Behavioral Therapists, Researchers, and other professionals at $600-$700 per person (UCLA).

PRT (Pivotal Response Training). PRT is a naturalistic intervention derived from ABA (Iovannone & Anderson, 2022). At one time, the program treated toddlers through their REACCH program (reported as CLOSED), school-aged children's programs, teen hangout groups, adult programs, and PEACE (Parent Education and Community Experience) (https://education.ucsb.edu/autism). Treatment is currently limited to adults who live in California – including treatments delivered virtually. The initial screening for adults costs $100, but if the patient is a resident of California and is approved for their program, there may be no additional cost (https://education.ucsb.edu/autism). Professional certification is reported to cost $800 for their 2-day workshop but has not been scheduled since November 2019, citing COVID-19 (https://education.ucsb.edu/autism). The PRT can be accessed through AIMS online modules for free without credit or a fee of $30 to receive a certificate (https://autisminternetmodules.org).

RDI (Relationship Development Intervention). RDI is available to parents via consultants (licensed professionals). Consultants of RDI teach parents to guide their children in reciprocal relationships, motivation, communication, emotional regulation, episodic memory, rapid attention-shifting, self-awareness, appraisal, executive function, flexible thinking, and creative problem-solving (https://www.rdiconnect.com). Treatment cost varies based on the consultant. Consultants are listed on RDI's website so patients can select someone from their state. RDI is available to licensed Psychologists, Speech-Language Pathologists, or others in related fields to train as RDI consultants. Consultant training is 12 weeks long and consultants must recertify each year (https://www.rdiconnect.com).

TEACCH® (Treatment and Education of Autistic and Communication Handicapped Children). TEACCH® encompasses the following principles: physical environment, predictable sequence of activities, visual schedules, routines and flexibility, work/activity systems, and visually structured activities (https://teacch.com). TEACCH® is in North Carolina and limits treatment to residents of North Carolina who can attend sessions in person. They offer two virtual TEACCH® Certified Practitioner programs, as all in-person training events have been canceled, which are listed as 5-day classroom training and a seminar. The cost for the Level 1 practitioner is $1000 for the application, exam, portfolio review, and certification fee, with a 3-year recertification fee of $225 and the cost of attendance at TEACCH®'s required 8-hour CEU training (https://teacch.com). The level 2 advanced consultant certification requires the practitioner to have been certified at level 1 for at least one year, and costs an additional $1000 for the application and certification fee, with a 3-year recertification fee of $525 and the cost of attendance at TEACCH®'s required 8-hour CEU training (https://teacch.com).

Therapies

Therapies are not intervention programs. Therapists in any field may have specific training or experience that fits the need of the student and family. It is the responsibility of the caregiver to consult with each therapist to determine if they are the right fit for their student. Behavioral, Occupational, Physical, Social, and Speech therapies may be available depending on where the student lives and what provisions are made for intervention services within the state or country. Usually, occupational therapy, physical therapy, and speech therapy are available in public schools at the minimum (Janus et al., 2019). Therapists may work independently or in collaborative teams. Collaborative teams are most likely to engage in focused intervention practices within a comprehensive treatment program (Sam et al., 2020; Schott et al., 2020; Singh et al., 2019). Therapies may be one-on-one or in groups, conducted at home, in the community, at school, or in a clinical setting.

Cognitive behavioral therapy (CBT) encompasses four different types: mindfulness-based cognitive therapy, dialectical behavior therapy, acceptance and commitment therapy, and rational emotive behavior therapy (www.abct.org). Applied Behavior Analysis (ABA) therapy is a recognized branch of behavioral therapy where a child works one-on-one with a practitioner (www.autismspeaks.org).

Occupational therapy (OT) addresses fine motor movements such as writing, self-feeding, self-care, and other activities of daily living; habits, routines, roles, and rituals; and social interaction skills (www.aota.org).

Physical therapy (PT) addresses gross motor movements like walking, jumping, and improving the range of motion of large muscle groups to build or restore musculoskeletal function; attainment or restoration of the maximum individual autonomous function for living as independently as possible through adaptation of visual, balance, mobility, and muscle impairments during activities of daily living; addresses physical movement to improve the functional independence of people who have cardiopulmonary conditions; and addresses physical or neurological abnormalities in pediatric patients who have injuries, congenital disabilities, developmental delays, or disease (www.apta.org).

Social therapy is often the domain of a Speech-Language Pathologist but may also be addressed by a social worker, psychologist, or psychiatrist.

Speech therapy (ST) is also the domain of a Speech-Language Pathologist (SLP) who addresses receptive language (cognitive-communication skills: problem-solving, memory, sequencing, and organization), expressive language (articulation, fluency, voice and resonance, and using cognitive-communication skills during communication), social communication, swallowing, feeding, and alternative communication modalities (i.e., alternative augmentative communication (AAC), sign language, picture exchange), if necessary (www.asha.org).

NOTE: When selecting an intervention program or specific EBP, each student must be considered individually – taking into consideration associated medical conditions and medications that have been prescribed (Doshi-Velez et al., 2014; Owen et al.,2017; Singh et al., 2019).