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Lived Experiences of Parents With Children With Autism Spectrum Disorder Transitioning to Adulthood

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Abstract

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Currently, there is little known about the parent experiences of transitioning their child with autism spectrum disorder (ASD) to adulthood from a qualitative perspective. The purpose of this qualitative phenomenological study was to explore parents' lived experiences as their ASD children transition to adulthood. This study was grounded in symbolic interactionism, which includes tenets of how interactions with others provide a catalyst for meaning development and subsequent human action. A phenomenological design was used with a purposeful sample of 10 parents of children with ASD transitioning to adulthood. Interviews were conducted through phone calls to explore participant perspectives transitioning their child with ASD to adulthood. Thematic analysis was applied to the data by coding, categorizing, and building themes from the parent information. Results indicated that parents experienced negative outcomes during pre transitioning and post transitioning, reporting that their child transitioning to adulthood did not have access to transition planning and preparation, that employment and postsecondary school supports were limited, and that their child continued to be dependent on the parents for all their needs. The knowledge gained informed professional practice in the needed areas of adult ASD transitioning. Affecting positive social change for parents of young adults with ASD is meaningful to improve outcomes for adults with ASD. This study provided a foundation for future research in this specialized area of life transitions.

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Dedication

To my beautiful son, Adam. Reach for your dreams despite the obstacles. I believe you can do anything.

To my husband, Michael. Thank you for being my editor, counselor, cheerleader, and biggest fan who always pulled me up to a new elevation that surprised even me. You made me believe I can do anything.

Acknowledgments

I would like to acknowledge my chair, dissertation committee, and dissertation family. Thank you for your leadership, guidance, support, and patience bringing me through this journey. My success is reflective of my solid, caring support system.

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Chapter 1: Introduction to the Study

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that presents with varied levels of communication, social, behavioral, and sensory challenges (American Psychological Association, 2016). The National Institutes of Health (NIH, 2018) reported estimated rates of ASD in the United States climbing to one in 68 children and 4.5 times more likely in males. In addition, more children with ASD are entering adulthood and will experience changes navigating and adjusting during this challenging milestone.

In this context, the aim of this study was to explore adult transitioning from the parent perspective. Parenting a child with ASD requires a creative approach to addressing characteristics such as social, sensory, and communication challenges that interfere with functioning (Andersson et al., 2017; Hartley et al., 2016; Williams et al., 2017). More specifically, parents face challenges when a child moves from secondary school and community programs that have been providing services to this population to independent life with little or no supports to help the parents navigate the burden of financial, emotional, social, and leisure needs of their young adult children (First et al., 2016; Milan & Nicolas, 2017). Parents report that they are still providing supports because their child has “aged out” of the programs in their communities and are no longer eligible, but their roles and coordination processes continues as well as their advocacy efforts to access services for their adult children (Milan & Nicolas, 2017; Platos & Pisula, 2019). As a result, there is limited social integration, poor outcomes with employment opportunities, and a lack of understanding of how to reach positive mental health, occupational, and social outcomes (Anderson et al., 2016; Howlin & Magiati, 2017; Wittenburg et al., 2019).

This chapter begins with background research associated with ASD in the context of children transitioning to adulthood with ASD and through the lens of the lived experiences of parents coordinating transitioning needs and supports. The background is followed by the problem statement and the gap in research, research question, theoretical framework, nature of the study, key term definitions, and assumptions about the research design and methods that may affect results. Finally, the chapter concludes with the scope and delimitations, limitations, significance of the study, and a summary of the information presented.

Background

It appears from the literature that children with ASD who are transitioning to adulthood often experience negative outcomes associated with employment, socialization, college access, and community integration (see Chen et al., 2018; Shattuck et al., 2020). Sosnowy et al. (2018) identified a disconnect with the expectations of services necessary to support young adults and the poor outcomes for young adults entering adulthood that includes lack of employment, skills to be affective in independent living, and lack of secondary educational opportunities. In addition, Spiers (2015) explored the status of parent responsibilities while a child with ASD transitions to adulthood and found that parents must continue to coordinate all areas of their child’s life well after high school has ended. Milestones that are associated with parents who are no longer caregivers to their children as they enter adulthood are often not occurring because of the parents need to continue provide care to their children into adulthood (Marsak & Hopp, 2019; Marsack & Perry, 2018). Further, research in adult transitioning with ASD show the need for supports in employment, daily life needs, and independent living skills, but there is continued gaps in service provision, understanding of individual needs, and resources and supports needed to meet goals associated with independence in adulthood (Kuo et al., 2018; Nicolas et al., 2018; Taylor et al., 2015).

Currently, several researchers have addressed the sudden increase in diagnosis of ASD and the development of specialized services required to meet the needs of this population (see Christensen et al., 2018; Hull et al., 2017; Maenner et. al., 2020). A large majority of research is associated with early intervention and school age children with ADS, with only an estimated 2% focusing on adult transitioning for young adults with ASD (Este et al., 2019; Shattuck et al., 2020). In addition, Herrema et al. (2017) noted that many families worry about their child's needs, their happiness, and if all the care supports will be available as an adult with ASD. Because a growing number of young adults with ASD (500,000) will reach adulthood during the next 10 years, more parents will be experiencing the phenomenon of extended caregiving firsthand (NIH, 2019; Paradiz et al., 2018).

Finally, there is less known through qualitative research about the parenting experience caring for their children with ASD who have transitioned to adulthood (Anderson et al., 2018; Ellenburg et al., 2018). Sosnowy et al. (2018) noted most quantitative data show consistently negative outcomes and often uses information from standardized tests and national survey banks that apply normative values to the experience of transitioning to adulthood and use varied methods and analysis approaches to conclude results. Further, rating scales and large quantitative study sampling used wide ranges of demographic information from single autism networks, outcome definitions and values varied, and most quantitative studies were not considering the lived environment of the person under study in the context the phenomenon was occurring (Anderson et al., 208; Gotham et al., 2015). My qualitative study is needed to address the knowledge that parents can offer to expand understanding of children with ASD transitioning to adulthood.

Problem Statement

Based on the background information, the research problem stems from the lack of continued programming and services after a child with ASD enters adulthood and an overall gap in individualized service provision (see Hendrickson et al., 2017; Nord et al., 2016; Snell-Rood et al., 2020;). Further, qualitative research focusing on in-depth, rich methodologies are lacking. Most of these studies were designed to understand general norms and were not tailored to recognize individual differences that contribute to success or failure transitioning to adulthood with ASD (see Cheak-Zamora et al., 2017; Robertson et al., 2018). Yet, Hamuth et al. (2018) found important factors associated with successful adult transitioning that includes individualized, person-centered supports, possession of job skills specific to certain vocations, informed communities and workplaces, and on-site job coaching.

In addition, transition planning in secondary school, which is an educational necessity for children with disabilities and other disorders, occurs less for those with

ASD (Hendrickson et al., 2017). Moreover, all specialized programming in education is no longer a legal requirement through the Americans with Disabilities Act (IDEA) after age 21 years, placing the burden of programming and care on parents and families (Papay et al., 2018; Pellicano et al., 2018). The federal education initiative to provide funding to schools focused on academic performance based on set core standards is in direct contradiction of specialized, individualized programming required for students with ASD and other disabilities (Deas, 2018). This trend in valuing standardized academic performance adds an additional barrier for children transitioning from secondary school to adulthood.

Although the research regarding parenting a child with ASD transitioning to adulthood illuminates important findings, I have found no qualitative research that has explored parents lived experiences of their ASD children transitioning to adulthood. Given such, further research is warranted that could explore parents lived experiences of their ASD children transitioning to adulthood to address the documented problem of children with ASD successfully reaching independence in adulthood (Cheak-Zamora et al., 2017; Gotham et al., 2015; Sosnowy et al., 2018).

Purpose of the Study

The purpose of this qualitative phenomenological design study was to explore the lived experiences of parents with children with ASD who are transitioning to adulthood. A phenomenological approach was appropriately aligned because I wanted to know the essence of how parents understand the transitioning process through their lived experience of their child's journey to adulthood. The research approach included identifying the essential structures or essence of the experience to concretely describe the population's world view (Hopkins, et al., 2017). Researchers have found that parents of children with ASD transitioning to adulthood continue to support and coordinate all areas of their child's life well into adulthood (Spiers, 2015; Paradiz et al., 2017). The gap in the literature stems from the lack of qualitative research exploring the lived experience of adult transitioning from the parent viewpoint (Sosnowy et al., 2018). The information from the study provided the full spectrum of the phenomenon regarding parent's view of changes in accessibility of services before and after transitioning to adulthood, how they cope with changes for themselves and their child with ASD, and what parents identified as necessary programming and barriers to their child's success as an adult.

Research Question

What are the lived experiences of parents with children with ASD during their child's transition to adulthood?

Theoretical Framework

The theory that was fitting for this qualitative study is symbolic interactionism (SI). This theory was brought to a more pragmatic and complex level by Mead (1934) who expressed the importance of how the world shapes individual behaviors through creating meaning when interaction occurs. Mead argued that interaction between individuals create shared interpretations and that the shared understanding of what meaning is placed on experience occurs within the context it is happening. SI is described by Alder-Nissan (2016) as a broad landscape of designs such as phenomenological, social semiotics, and narrative approaches, to name a few. The basic tenets include placing subjective meaning to objects, interaction of people and objects occur in relation to culture and social situations that are assigned a category within that context, interaction with others create meaning, and meanings are continually created and revised based on social interaction (Carter & Fuller, 2016). In addition, SI requires the researcher to gain first-hand knowledge from the social entities immersed in the natural world; data that is collected are summarized and categorized in an organized fashion, and data analysis results in relationships between categories (Salvini, 2019). SI theory is vital to understanding and interpreting meaning of parents of children with ASD and how their actions shape how adult transitioning transpires.

SI helped me to identify the social influences within the family, community, teachers, programs that shape the lived experiences of parents with ASD children transitioning to adulthood. Specifically, I hoped that the parents express how and why certain actions were taken prior to transitioning and after, showing the effects these actions had on relationships and their child's level of success. The interview questions were grounded in SI because the structure was open-ended and emergent based in the individual responses and meaning that is assigned to the phenomenon. The use of SI helped inform me what parents define as meaningful supports, resources, and programs by identifying what is significant and necessary for their child's success as an adult. In this light, the gaps in service provision interfering with successful transitioning and communication breakdowns within relationships can become apparent and addressed on a broader community level.

Nature of the Study

This study was qualitative in design with a phenomenological approach; this approach best aligned with my study's purpose and research question. A phenomenological approach was appropriate because the process attempted to explore the life story, beliefs, experiences, and constructs and assigns meaning to the phenomenon by creating common themes (see Adams & van Manen, 2017; Corby et al., 2015; Hopkins et al., 2017; Noon, 2018). The process allowed for my research to identify the lived experience of parents who have specific experience and knowledge of the adult transitioning process of their children with ASD and aligns with SI theory. A phenomenological approach requires an emergent design that allows for participants to describe their lived experience, moments, stories, anecdotal accounts, so the researcher can capture the essential, consistent, shared structures of the phenomenon (Hopkins et al., 2017). Interviews with open-ended questions were used as a method to gather data. This method was appropriate because it allowed for individual and contextual responses that are unique to the participant, eliciting the most in-depth and rich information. My research question spoke to the need to find the essence of what the experience means to these individuals. Seidman (2012) noted that interviewing as a form of data gathering is time consuming and costly, but necessary if the true meaning is to be identified in phenomenological research.

The procedures included informed consent confirmation and institutional review board (IRB) approval prior to the start of the process. One on one phone interviews with parents who have children with ASD transitioning to adulthood were conducted with each participant. All participants were contacted by email or phone to confirm a time and to answer any questions they had about the process. The interviews occurred at a time that was convenient for the participant and in their own setting of choice. The interviews included questions that were open-ended and emergent, requiring changes and additions as each interview progressed. The interview guide was used for all interviews and consisted of 10 questions to answer my research question. Interview guidelines are necessary because they provide a standard to increase the amount of rich, relevant, and long answers from the participants, while consistently circling back to the main assumptions of the interview to improve quality and trustworthiness of the research (Roulston, 2010). The phenomenological terms such as descriptions, perceptions, their view of the parent experience, what was their own meaning of experiencing transitioning, and what was their specific story, were included in the interview questions. I conducted the interviews journaled, completed field notes, and memos throughout the process.

The questions were neutral, open-ended, congruent with the level of education and understanding of the participants and were changed as needed, as recommended by Saldana (2015). I began with probing questions, expanding the continued discussion based on the participants responses (see Saldana, 2015). Multiple questions were not asked together and there were no leading questions to force a respondent to answer in a certain way. In addition, I provided an introduction and closure statement in the interview guide in the form of a script, so I was prepared beforehand to describe all the components of the interview, consent process, and interview expectations, ending each interview with assurances regarding the handling of data, confidentiality, study results, and answered any questions generated by the interview process.

The initial recruitment and data collection process included partnering with an organization who provides support for people with ASD and their families. However, after weeks of reaching out to like agencies with no success, recruitment changed to snowball sampling and through a Facebook flyer. Snowball sampling approach was appropriate because there is a need to include only individuals who have experienced this phenomenon who meet set criteria, and who are hard to find. Because this study required a need to access remote and motivated participants who were parents experiencing adult transitioning of their child with ASD, snowball sampling was aligned with the approach.

The participant inclusion criteria were comprised of parents of children with a formal diagnosis of ASD, ages 18-26, and who completed the transition to adulthood. The participants were vetted, and I excluded all parents who self-diagnosed young adult children, parents of children with ASD who have not lived at home, and parents who chose not to participate in the study during recruitment. Proof of diagnosis of ASD by a licensed professional based on the Diagnostic and Statistical Manual-V (American Psychological Association, 2016) diagnostic criteria and proof that the child had lived at home during transitioning were required to participate in the study. Criteria expectations were part of the recruitment email. The inclusion criteria were directly associated with the population, the process of transitioning to adulthood, and the characteristics of the parents in the sample. Inclusion and exclusion characteristics and criteria allow s a researcher to purposefully select the individuals, setting, event, and processes within the parameters of the research question (Maxwell, 2012). Once parents met the criteria by agreeing to participate, signing required informed consent, and providing required diagnosis and residency documentation, I contacted 10 participants through email or phone for their availability.

I initially planned on a sample size of 8-12 participants. Mason (2010) indicated that phenomenological studies are generally between five and 25, but no less than six. The number of participants was chosen because it appeared to be a feasible group to recruit and interview within a reasonable time period with only one researcher. Although many experts rely on saturation or when there is no more new information to gather to identify sample number, Guest et al. (2006) stated that there are no hard guidelines to identify the right number of a sample prior to starting the research and that the process of saturation occurs during the data collection process. On the other hand, Mason (2012) differentiated the needs of Ph.D. researchers who are often required to confirm sample amount and justification prior to beginning the research. The small size included parents who met the inclusion criteria and were considered to have the most amount of rich information and could had the greatest effect on the study. The initial 8-12 participants decreased as saturation was reached at 10 interviews in the coding process and when there was no new information captured.

Thematic analysis was used to analyze data generated from the interviews and my researcher notes. Thematic analysis was appropriate because the raw data unfolded and provided patterns identified through codes, categories, and themes which assigned meaning to the daily experiences (see Saldana, 2015). Thematic analysis is appropriate for phenomenological approaches because the process attempts to explore the life story, beliefs, experiences, and constructs and assigns meaning to the phenomenon by creating common themes (Saldana, 2015). Thematic analysis provided credibility to the research because it is a well-established method applied to phenomenological frameworks. Research credibility refers to the plausibility of the study and is accomplished by creating reliability, replicability, accuracy, and consistency (Tracy, 2010). In addition, dependability and confirmability were strengthened through an external expert versed in phenomenological design and thematic analysis who will audit the research data, memos, journals, and analysis results. This provided a layer of transparency to the research analysis process.

The role of the researcher is important when applying a phenomenological approach. The phenomenological approach includes the researcher as the primary instrument and required my ability to understand my own positionality. The focus needed to move between the general essence and the idiographic experiences of the parents, bracketing and reflexivity must be applied to balance preunderstandings of the phenomenon, and special care must be taken to write and articulate the issues (Hopkins et al., 2017). In addition, biases must be addressed during all parts of the writing process through journaling and note taking.

Further, research credibility associated with qualitative inquiry must include strategies to prove dependability, transferability, and confirmability that validate the trustworthiness of the reconstructed research results (Morse, 2015). To create credibility, I provided member checks with participants throughout the interview process, once interviews are transcribed, and after the results are synthesized. Also, peer-debriefing by my chair and committee was paramount to the accuracies of my interpretations and processes. Triangulation was achieved through peer debriefing from other researchers, participants, and outside expert auditors and review boards to confirm or question accuracy.

I provided an audit trail to identify my decision choices and spent prolonged time with the participants reviewing and re-reviewing the data. Hadi and Closs (2016) acknowledged that an inquiry audit can improve quality and trustworthiness and improve rigor in qualitative research. Further, Morse (2015) described how thick description is accomplished by spending a prolonged amount of time with the participants to achieve authentic, natural responses. Finally, a reflexive journal was used throughout the process to examine my own beliefs, decisions, and how or if it influenced the research process. Cunliff (2016) described how reflexive journaling improves how reality is described and constructed.

The researcher must include safeguards not to cause harm to all participants and stakeholders involved in the research study. Rubin and Rubin (2012) emphasized respect and honesty, do not harm, exploit, or pressure, and follow established IRB regulations. Exploitation can occur in many forms. Seidman (2006) stated that there is an inherent imbalance of power between the researcher and interviewee because the researcher may be perceived as exploiting the participant for scholarly gain. I provided all participants with informed consent, the sample selection process followed IRB guidelines, and I was vigilant through the entire research process when potential ethical dilemmas surface.

Cypress (2018) moved the ethical issue forward by considering where the interview will take place, protecting participant consent and rights, having a strategy for sampling appropriate for the research, planning how the information is collected, and how the information is disseminated.

Definitions

The following are key terms that were used throughout the study:

Affiliated stigma: Internalizing stigma felt by a person that is associated with the stigmatized person (Zhou et al., 2018).

Autism spectrum disorder (ASD): A neurodevelopmental disorder that presents with communication difficulties, social interaction and sensory challenges, repetitive behavior, and restricted interests (American Psychological Association, 2018). Autism, autistic disorder, autism spectrum condition, Asperger syndrome, and ASD are used interchangeably.

Entitlement programs: Individualized educational programing and planning and transition planning provided throughout childhood until age 21 with a diagnosed disability, supported through the IDEA regulations (Deas, 2018).

Guardianship: A legal trust relationship to protect an individual with illness/disability and make decisions associated with personal and public vulnerabilities (Kelly et al., 2020).

Mainstreaming: The process of inclusion for those with special needs classified as developmentally disabled in normally developing peer educational environments (Wood, 2019).

Person-centered planning: When the focus of the educational, habilitative, or care planning begins with the needs, values, and presentation of the person involved (Anderson et al., 2016).

Resonance: A theoretical construct that assumes that views beliefs, and attitudes can be different from the larger shared view of a phenomenon (McDonnell et al., 2017).

Self-determination: An inherent process where people make choices to engage in certain ways because they are internally motivated to participate (Shogen et al., 2018).

Symbolic interactionism: A theoretical framework that assumes constructs are developed when a person interacts and responds to relationships, objects, the environment, and assigns meaning to the experiences that will affect action (Blumer, 1969).

Assumptions

For this study, I applied a phenomenological design which assumed that people had a shared essence of what it is like to experience an event or situation in the specific context that it occurs (see Hopkins et al., 2017). More specifically, I assumed all parents have experienced adult transitioning with their children with ASD and that they understand the effects of the phenomenon based on their contextual influences. I assumed that I offered a platform for parents to openly reflect on the lived experience and that they are engaged in their child’s life. Last, I assumed that all information I gathered from parents were honest and given in good faith. These assumptions are important because the study goal was to achieve credible, authentic, and rich information from the parent experience.

Scope and Delimitations

This study intended to address the lived experiences of parents who have children with ASD transitioning to adulthood. There is a gap in service provision once children transitioning to adulthood are no longer eligible for secondary school entitlement programs. Only parents with children 18-26 years old were chosen because they were the most experienced and knowledgeable on the adult transitioning phenomenon. In addition, the sample size was small (10) and only included parents who had children with a formal ASD diagnosis. This provided a more credible depiction of the phenomenon that was in-depth and thick with qualitative descriptions of the experience. The initial recruitment and data collection process included partnering with an organization who provides support for people with ASD and their families. However, after weeks of reaching out to like agencies with no success, recruitment changed to snowball sampling and through a Facebook flyer. It served to find an expert panel of remote parents willing and able to participate in this study. Although a small sample, this study attempted to achieve transferability by having expert instructors and auditors review all design, data collection methods and results, member checks, peer debriefing, reflexive journaling, and triangulation through prolonged time with participants to achieve authentic, thick descriptions of the phenomenon.

Limitations

There are multiple challenges that were addressed while conducting this study. First, in qualitative research, the researcher is the primary data collection instrument and has the potential to influence the process and results of a study (see Patton, 2015).

Transparency throughout the research process must be obvious to address subjective views that could affect the trustworthiness of the results. These biases must be addressed during all parts of the writing process. To address the researcher positionality as the primary instrument of the study, a 3-1 phenomenological framework was employed. Documentation was used through journaling and memos prior to the research and throughout the recruiting, interviewing, data analysis, and result stages. This documentation strengthened the trustworthiness of the results by identifying accuracies and inconsistencies between participants based on the interpretation of the researcher experience.

Next, the COVID-19 pandemic impacted how I accessed participants for a phenomenological study. Although face-to-face interviews are considered the gold standard to access the richest and most authentic data (McGrath et al., 2019), peer-to-peer phone interviews were used. Finally, there was a back-up plan for issues that occurred recruiting because the nonprofit agency that advocates for children and family issues addressing ASD was unwilling to help recruit through their email system. Snowball sampling through a Facebook flyer was applied to parents who have children with ASD transitioning to adulthood who are considered hard to find.

Significance

This research filled the gap in understanding the experiences of parents with children transitioning to adulthood who are diagnosed with ASD. The study provided much needed insight into parents lived experiences while their child with ASD transitions from adulthood and focus on what it is like from the parent viewpoint (see Este et al., 2019; Shattuck et al., 2020). The key players that could benefit from this research are parents in northern New York with ASD children, nonprofit organizations that provide support and services such as Wildwood Programs, Center for Disability Services, Prospect Child and Family Services, Albany Warren Washington ARC, Community, Work, and Independence, Inc., and agencies advocating for families such as Autism Alliance, Office of People with Developmental Disabilities (OPWDD) and New York State Association of Community and Residential agencies (NYSACRA). Understanding the phenomenon from the parent perspective was critical because the information has the potential to affect resources, funding, programming, and life skill development currently lacking after the transition phase (First et al., 2016; Milan & Nicolas, 2017). The knowledge gained informed professional practice in the needed areas of pre-planning programs in social skill training, competitive employment training, budgeting, and life skills training, and affect advocacy, grant availability, and policy development that supports successful adult transitioning (Kuo et al., 2018; Nicolas et al., 2018; Taylor et al., 2015). Whatever the potential implications, affecting positive social change for parents of young adults with ASD is meaningful for these reasons and this study may have the potential to provide a foundation for future research in this specialized area of life transitions.

Summary

In Chapter 1, I provided an introduction to ASD and the challenges parents face when their child with ASD transitions to adulthood. Background information described the vast amount of research regarding negative outcomes for young adults transitioning to adulthood including the lack of competitive employment opportunities, access to college, opportunities for relationship building, and the lack of opportunities to develop skills necessary for independent living (see Shattuck et al., 2017). In addition, parents continue to provide supports long into adulthood for their adult children with ASD (Spiers, 2015). The problem statement includes the lack of qualitative, in-depth studies focusing on the parent perspective navigating adult transitioning for their child. The purpose of this qualitative, phenomenological study was to contribute to the knowledge of the parent lived experience transitioning their child with ASD to adulthood and add to the discourse from a qualitative perspective. The research question, a qualitative phenomenological design, significance, and methodology were aligned to provide an avenue to answer what it is like to experience adult transitioning with ASD from the parent's point of view.

Chapter 1 provided theoretical overview for how SI tenets can be applied to explain parent's actions, decision making processes, and reactions to the phenomenon. As the chapter concludes, assumptions, delimitations, scope, and limitations are reviewed to set a ground for future research related to the phenomenon. Chapter 2 transitions to a comprehensive review of current research in the areas of ASD associated with parenting, employment, socialization, postsecondary education, programs, and services, highlighting the theoretical foundation of SI and how the effect of adult transitioning effects parent communication, behavior, and relationship dynamics.

Chapter 2: Literature Review

This qualitative phenomenological study was centered on identifying the lived experiences of parents who have children with ASD transitioning to adulthood. The objective was to better understand how parents experience this challenging phase of their child's journey and what are their needs or unmet needs during their child's transition. This study contributed to academic literature on adult transitioning for people with ASD because the focus is on the parent experience of the phenomenon that is currently lacking in the research (see Shattuck et al., 2020; Sosnowy et al., 2018).

The literature was organized into six sections: (a) ASD and characteristics (variability, camouflaging, sensory processing, gender, diagnosis disclosure), (b) education (transition planning, mainstreaming, marginalization and bullying), (c) postsecondary education, (d) competitive employment, (e) parenting research associated with ASD (parent education and instruction, stigma, relationships, parent differences, financial issues, healthcare and insurance, and guardianship), and (f) an in-depth review of the theoretical framework and constructs associated with symbolic interactionism and other theories related to assigning meaning to learning and behavior choices, meaning negotiation, and development of how theory relates to parents.

Literature Search Strategy

In the literature review, I focused on identifying information regarding young adults with ASD transitioning to adulthood from the parent lived experience. I implemented an electronic search of academic libraries such as the Walden Library and Google Scholar and organizational websites (National Institutes of Health and autism organizations). The following databases were used to find peer reviewed articles SocINDEX, PsychINFO, Proquest Central, Sagepub, Psycnet, nih.gov, academia.edu, researchgate.net, plos.org, springer.com, jamanetwork, semanticscholar, ERIC. The following search words and phrases were used: *phenomenological, qualitative study, symbolic interactionism and autism, autism spectrum disorder and parenting, ASD and sensory processing, ASD and gender, ASD and diagnosis disclosure, employment, services, college, education, autism and transitioning to adulthood, ASD and caregiving, autism and parenting stress, autism and secondary education, autism and guardianship, parent styles, autism and insurance, autism and siblings, ASD and marginalization, stigma, affiliated stigma, ASD parenting and resources, autism and guardianship, autism and camouflaging, ASD parent differences, ASD and bullying, ASD and healthcare, ASD and transitioning, transition planning, parent instruction*, *and parent education.*

Theoretical Foundation

To provide a foundation for understanding the parent lived experience of their child transitioning to adulthood, the overriding social theory that emerged in the literature review was SI. SI provided a theoretical framework that assumes constructs are developed when a person interacts and responds to the environment and assigns meaning to the experiences (Blumer, 1969). SI was transformative because it shifted from a macroview of constructs that focused on how society shapes norms and rules of other's beliefs and actions, to a microview of how an individual makes sense of society through interactions with others through a social process within the society (Carter & Fuller, 2016). In other words, people shape their own social world that is ever changing and emergent, influenced by others feedback and interactions, with the outcome of developing shared understanding but an understanding that individuals have a unique worldview (Carter & Fuller, 2016).

The basic tenets of SI include how individuals act in response to meaning assigned to objects, events, people, there are shared classifications in social settings, meanings emerge from continued engagement, and meaning is not static in that individuals may no longer subscribe to certain meanings and develop new ones over time (Denzin, 2016). Franzese and Seigler (2020) described SI as a social process that conditions behavior based on time and context the interaction is occurring, and that human beings adjust how they act if expectations are not met. Therefore, individual identity and societal role is determined and modified based on how things are interpreted and understood (Šijaković & Vilić, 2019). Further, Adler-Nissan (2017) considered SI as a broad range of approaches that can be applied to varied methods that include phenomenology, social semiotics, ethnography, and narrative approaches, to name a few. Although from differing viewpoints, all share similar assumptions in that human behavior is understood within the context of their community and is always intersubjective, social life and situational meaning differs from people and groups, and the self-reflexive nature of learning and taking on other’s viewpoints and behaviors is always emergent and incomplete (Adler-Nissan, 2017). These constructs appear to be universal when applying SI.

SI has been applied to understand social constructs on multiple phenomena. Because the causes of human behavior move beyond basic interaction, Utzumi et al.

(2018) regarded SI as a foundation to identify how the person is conditioned within health care and is an active participant along with the provider to monitor health and wellness. Panicker et al. (2020) applied SI to understand habits formed with intergenerational families regarding shared food and eating rituals. Panicker et al. (2020) found that role changes within the family dynamic can be explained within the influences of the home environment. SI tenets have expanded understanding of politics and human rights in varied countries by interpreting how individuals behave within a system that controls citizens at the macro level but is influenced at the micro level to make sense and respond to the system (Richard et al., 2017). In addition, SI within the context of education can be applied to better understand student teacher relationships and factors associated with teacher and student satisfaction and self-efficacy (Tsang & Jiang, 2018). Thus, researchers from various sciences and philosophies can apply SI constructs within multiple phenomena.

SI includes one important construct: an ability for a human being to continually negotiate individual meaning of their experiences and change their behavior accordingly, but not always in agreement with others who experience the same phenomenon (Carter & Fuller, 2016). This deviates from pragmatist theory because McDonnell et al. (2017) described how the theory of resonance provides a construct to understand SI in the context of the individualized experience as not an overarching shared congruence or agreement to a cultural object or event. Resonance provides a way to understand how social change occurs because of the discourse associated with an object, event, or experience (McDonnell et al., 2017). Resonance includes micro, meso, and macro levels of theoretical understanding to recognize how people solve complex problems when their worldview is contentious or different from the shared view of a phenomenon (McDonell et al., 2017). McDonell et al. (2017) illustrated how resonance theory comes into play when a Ghana community attempted to start an advertisement for HIV education and found that many differing viewpoints had to be considered that moved away from the idea of death, moving forward toward proactive healthy behavior. Resonance theory appears to provide an extension of SI regarding how the context of a cultural experience is interpreted from different angles even though it is considered initially as the same shared experience (Hall et al., 2017). Therefore, researchers recognize through the foundation of SI how phenomenon is experienced contextually and over time (Carter & Fuller, 2016).

Scholarship on ASD and symbolic interactionism has been applied in combination with other theories and methodologies across disciplines (Adler-Nissan, 2017). Leveto (2018) described the move toward understanding autism through a sociological paradigm that offers solutions to improve quality of life based on identifying inequalities, stigma, interplay of the individual and society, and the acceptance of neurodiversity. Because one of the important constructs of SI includes understanding the role of others, people with ASD are discounted based on certain theories that view successful self-development requiring this ability (Leveto, 2018). Many of those with ASD have communication difficulties, are not able to take the perspectives of others, and strictly adhere to certain routines and behavior (Anderson et al., 2016). For example, theory of mind (ToM) is a widely accepted and applied to understand how people understand their social environment and self-regulation from internal mental states that occur through interaction (Hamilton et al., 2016). When applied to ASD, ToM is lacking because it cannot be constructed if there are deficits in communication and language (Hamilton et al., 2016). Therefore, it is thought that ToM cannot be achieved for those with autism because impairments in social cognition will cause life-long interference in social development (Leveto, 2018).

In contrast, During (1996) described the theory of meaning that includes the "crisis in meaning" that requires others to understand autism from the viewpoint of autistic people and not from what we interpret as meaningful as a society. This approach compliments SI in that the goal is to find deep shared meaning in experience and interaction from the individual's perspective (Leveto, 2018). In addition, Livingston et al. (2019) determined that many individuals with autism have compensatory skills that allow them to develop a theory of mind despite cognitive deficits. Executive functioning, anxiety and IQ level all are factors in how successful individuals with autism develop compensatory skills and not the severity of autistic symptoms (Livingston et al., 2019). It is important to understand how SI tenets explain the need to use compensatory skills for those with ASD and the ability to negotiate the social world, despite social, cognitive and communication deficits (Leveto, 2018). Within this context, compensatory skills appear to improve overall social adaption for people with ASD.

Literature Review

SI is aligned with exploring parent experiences of their child's transitioning to adulthood because it established a framework to understand how families and children with ASD develop their roles, acquire values and behaviors, and make decisions during this important milestone. For example, Totkova (2019) applied SI to parenting style and found that the unique challenges of ASD faced by caregivers influences family dynamics and relationships, and ultimately affect how decisions are made regarding ASD interventions and resources. Taken one step further, I explored how families construct what is valued and believed and how parents act toward changes that occur during the transition stage of their child's life. In other words, contextual factors experiencing this phenomenon may affect relationships, choices, and create shared meaning among parents of children with ASD transitioning to adulthood. Because people may experience the same phenomenon, some meaning may be shared but other meaning and following behavior differ from one parent to the other. This is the focus of this research and how it applies to the theory of SI, the parent experience of their child's adult transitioning, and what is believed to be true during this milestone.

ASD and Characteristics

To explore the lived experiences of parents who have children with ASD transitioning to adulthood, this literature review started with research to better understand ASD and how characteristics may affect adult transitioning. ASD is a neurodevelopmental condition characterized by repetitive movement and behavior, challenges with social interaction and communication with others, sensory input issues, and restrictive interests (American Psychiatric Association, 2013; Jackson et al., 2018; Masi et al., 2017). The presentation of ASD is varied and differs in severity and symptoms from one person to another (Ohl et al., 2017). As a result, the Diagnostic and

Statistical Manual was revised in the fifth edition to move from Asperger's or autistic disorder to autism that presents on a spectrum, now known as ASD (De Groot & Van Strien, 2017). Certain characteristics that are shared by children transitioning to adulthood contain restricted and often linear behavior and thinking necessary achievements that must be attained including personal responsibility for behavior, maturity in adulthood, and independent living (Anderson et al., 2016). These characteristics are like young adults without ASD and often not attainable if programs and services do not recognize the need to adjust transitioning planning to include individualized person-centered planning (Anderson et al., 2016). Expectations of parents affect how their child perceives themselves and their ability to reach successful milestones in adulthood. Thompson et al. (2018) found that parents of children with ASD do not want to marginalize their children based on their deficits and approach adult transitioning by leveraging their child's strengths and level of understanding. Because ASD characteristics vary so widely, it appears from the literature that care should be taken to recognize individual needs within a broad range of approaches (Shivers et al., 2019). Therefore, certain ASD characteristics may have different levels of severity based on growth rate and may interfere with successful transitioning.

The following subsections of the literature review provide specific characteristics of ASD that appear frequently in the literature. The variability of ASD characteristics, camouflaging characteristics, sensory processing issues, gender differences, and diagnosis disclosure all are described more thoroughly, with special attention paid to understanding these issues within the context of ASD and adult growth and transitioning.

ASD Variability

The literature review included differences in how ASD characteristics present, variability in characteristics, and when symptoms are more likely to occur. The findings suggest that ASD symptoms are heterogeneous and changes in symptoms during development occurs at different times (see Franchini et al., 2016; Geelhand et al., 2019; Pierce et al., 2016; Szatmari et al., 2015; Thurm et al., 2015; Van Eylen et al., 2015). Wozniak et al. (2017) described the diagnostic variability with ASD based on the required criteria of persistent deficits in social communication and interaction, restrictive interests and repetitive behaviors, and the presentation of atypical behavior in early development. For example, characteristics may vary and include lack of eye-gaze during conversation, lack of reciprocal gestures, limited emotional response, difficulty engaging in sustained relationships, perseverative language, resistance to change, hypo- or hypersensitivity to sensory input, maladaptive behavior that may include self-injury or verbal/physical aggression, and varied cognitive and intellectual impairments (Wozniak et al., 2017). To compound the variability, developmental growth changes the trajectory of what and when characteristics appear, often changing in ASD severity and presentation (Guo et al., 2017; Nunes et al., 2020). Further, the growth trajectory for ASD is not always a linear process and certain ASD symptoms may change in severity while other characteristics may newly appear to decrease in severity (Kim et al., 2018). In addition, across the lifespan ASD characteristics differ and fluctuate depending on sensory dysfunction issues and the ability to understand other's perspectives and points of view (Lever & Geurts, 2018). Therefore, it appears from the literature that no two children will have the same symptom severity, have the same symptom growth trajectory, or experience adulthood similarly.

The literature revealed that there is a subset of people with ASD that do not have a co-occurring intellectual disability, often referred to as high functioning ASD (Baker-Ericzen et al., 2015; Baldwin & Costley, 2016; Joshi et al., 2017; Lai et al., 2019; Ung et al., 2015; Wigham et al., 2017). Within this group, researchers have found a higher prevalence for anxiety, depression, and chronic sleep issues (Baker-Ericzen et al., 2015; Ung et al., 2015). In addition, more than two thirds of children with high functioning ASD are diagnosed with attention deficit hyperactivity disorder (ADHD), which may include impulsivity, hyperactivity, or inattention (Joshi et al., 2017). Yet, ADHD is often not recognized or properly treated for those with high functioning ASD (Joshi et al., 2017). Lack of treatment for ADHD may result in social, emotional, and academic issues when inattention or hyperactivity interferes with skill development (Zijac et al., 2018). These results indicate that it is necessary to identify those children presenting specific to this ASD subgroup to improve caregiving strategies, treatment needs, and individualized programming.

ASD and Camouflaging

There are specific factors associated with individuals with ASD that play a role in reaching success as an adult. Camouflaging or masking is the process of compensating for social and communication deficits that often interfere with relationship development and inclusion so the person with ASD “fits in” to their schools, families, and communities (Lawson, 2020). It appears from the literature that females compensate and use masking skills at a higher level than males (Lai et al., 2017; Parish-Morris et al., 2017). Although this skill may help to transition to adult living, there are negative consequences to camouflaging which may interfere with accurate diagnosis and services, and ultimately cause increased stress, self-perception issues, and exhaustion (Hull et al., 2017; Lawson, 2020). Wood-Downie et al. (2020) confirmed the increased use of camouflaging among females with ASD and how it contributes to lack of ASD identification and ASD supports. Robinson et al. (2020) described camouflaging as "reputation management" for those with ASD and that it occurs most often when they are attempting to fit in to their social group. Kim and Bottema-Beutal (2019) found that social acceptance and social skill development improves quality of lift indicators. Camouflaging has negative and positive results, with men appearing to experience depressive symptoms and women improving their ability to identify social cues (Lai et al., 2017). Cassidy et al. (2020) discussed the severity of the effect of camouflaging and how feelings of aloneness or feeling that people with ASD are a burden are exacerbated by hiding autistic traits and could lead to suicidal thoughts and behaviors. Based on these results in the literature, professionals and caregivers need to identify camouflaging to address and improve deficits through identification and early intervention.

ASD and Sensory Processing

Sensory processing dysfunction is a universal characteristic of autism and may include deficits in vision, touch, smelling, hearing, movement, and integrating multiple sensory input at once (Case-Smith et al., 2015). As far back as Kanner (1948), as cited in Case-Smith et al. (2015), sensory differences in touch, sound, movement, and fascination in lights that flicker have been well documented. Hypo and hyperactivity to external sensory input may produce interference in social activity and engagement with others and sensory behaviors are associated with both positive (attention to detail) and negative (hand flapping, repetitive behaviors) outcomes (Tavassoli et al., 2018). It appears that impairment in sensory processing can have ongoing, negative effects on achieving successful relationships and community integration (Baum et al., 2015; DuBois et al., 2017). Thye et al. (2018) researched the associated between sensory input dysfunction and social impairment for those with ASD and found that depending on the sensory dysfunction, certain symptomology will emerge throughout development. The authors explained how atypical vision processing such as lack of maintaining eye contact, impairment in face recognition, sensitivity to noise and lack of affective content and meaning in communication, tactile dysfunctions that interfere with bonding, and the lesser-known taste and smell deficits, produce atypical social behaviors (Thye et al., 2018). Sensory over responsivity (SOR), described in Green et al. (2018), was a hypersensitivity to sensory input such as loud noises and tactile stimulation and associated with interference in adaptive behavior and social skill acquisition. Overload of sensory input is associated with emotional deregulation that may produce maladaptive behavior such as verbal and physical tantrums, depression, anxiety, or self-injury, and may predict social and behavioral issues throughout development (Berkovits et al., 2017; Conner et al., 2019; Samson et al., 2015). In turn, negative emotional expression appears to effect caregiver stress and challenges their coping mechanisms to respond appropriately.

Sensory based interventions have shown to lessen the negative expression of hyper and hypo sensory sensitivity (Watling & Hauer, 2015). Watling and Hauer (2015) assessed widely accepted, evidence-based sensory intervention and found that active and repetitive engagement, sensory rich activity, motor planning, and customized sensory processing exercises using a ply-based model improved positive social engagement and emotional regulation. In addition, the Aryes Sensory Integration Intervention for children with autism is an evidenced-based program that has shown to improve self-regulation and motor-sensory development and provides a systematic protocol for individualizing interventions to meet each child's unique needs (Schoen et al., 2019). Yet, Weitlauf et al. (2017) found that after reviewing multiple studies, sensory interventions had only minimal positive effects from various sensory specific domains. Therefore, the literature results on sensory based interventions were inconsistent and there appears to be a need to customize sensory integration programming for those with ASD.

ASD and Gender

The literature review includes the differences between gender and the presentation of ASD diagnosis and symptomology. It appears there are differences in the amount and when females are diagnosed and how females with ASD experience and respond to challenges in executive functions, social integration, empathizing, and problem solving (Beggiato et al., 2017; Dean et al., 2017; Halladay et al., 2015; Hull et al., 2017; Rynkiewicz et al., 2016; Schuck et al., 2019). Camouflaging or masking symptoms to adjust to social situations is more common for females (Schuck et al., 2019) because they appear to be more socially motivated to access and maintain friendships (Dean et al, 2017). Yet, camouflaging may cause under diagnosis due to compensatory behavior used to fit in to social environments (see Dean et al., 2017; Rynkiewicz et al., 2016). Mandy and Lai (2017) reported that there may be under diagnosis among females because females do not score high on restrictive behavior criteria because they adopt stereotypical interests of their peers such as a love for animals or dancing. Although ASD affects males at a higher rate than females, it occurs across all races and socioeconomic groups, and because of the enormous growth in the diagnosis, development of specialized programs, and resources are needed to address ASD challenges (*Nih.gov*, 2018). Despite these advances, males, and females with ASD remain dependent on their families (50% in the U.S.) well into adulthood and continue to have communication and social interaction challenges, sensory input issues, and repetitive behaviors that interfere with community integration and independence (Cai, 2016). It appears from the literature review on gender differences that specific characteristics of ASD need to be identified early and may require different approaches based on male or female ASD presentation.

ASD and Diagnosis Disclosure

There is little known in the research about a child’s reaction to a diagnosis of ASD from their parent or practitioner (Eckard, 2019). Children with ASD internalize and accept their diagnosis based on the information that is shared, who shares the ASD information, and how early ASD is disclosed to the child (see Kiely et al., 2020; Sasson & Morrison, 2019). It appears that knowledge of diagnosis improves self-advocacy, diagnosis acceptance, and provides self-awareness of their ASD challenges and strengths (Kiely et al., 2020). Sasson and Morrison (2019) found that to remain anonymous and not be discriminated against, individuals with ASD are hesitant to disclose their diagnosis. There also appears to be a need to maintain a public image and a private image because of potential ridicule from their peers (Cox et al., 2017). Children and adults with ASD avoid disclosing their ASD diagnosis because of the potential for rejection from peers. In addition, Frost et al. (2019) found that young adults do not disclose their diagnosis and do not want to be associated with ASD services and supports so they appear to fit in with their social group. Both negative outcomes and stigma appear to be associated with diagnosis disclosure (see Thompson-Hodgetts et al., 2020). Based on the literature results, early disclosure and continued collaborative intervention is needed to improve ASD outcomes.

ASD, Education, and Transition Planning

In the U.S., children with ASD are provided inclusive education that is specialized for their needs (Eapen et al., 2017). The federal IDEA (Individuals with Disabilities Education Act) regulations in the U.S. are designed to provide inclusive, least restrictive, and specialized education programs for children with varied developmental disabilities until the age of 16 (Eapen et al., 2017). IDEA regulations include an Individualized Education Plan (IEP) and as the child ages out of eligible programming and an IEP transition plan (Papay et al., 2018). Transitioning at all ages throughout primary and secondary school requires a collaborative commitment from parents and teachers to increase participation, positive social relationships, and social skill development (Eapen et al., 2017). Specific to public schools, Locke et al. (2015) found that many schools do not provide quality interventions to students with ASD because they do not have available and trained staff and lack ongoing policy and supports to sustain intervention.

Yet, the literature includes many programs designed to address early intervention and primary education supports and interventions that are individualized to address ASD adaptive limitations, skill development, teacher effectiveness, academic performance, and decreasing negative behaviors (see Barnett, 2018; Estes et al., 2016; Finnegan & Mazin, 2016; Knight & Sartini, 2015; Rakap et al., 2015). Further, teachers and other personnel have moved from trying to change the characteristics of ASD to embracing individual skill sets and improving self-determination and advocacy (Wong et al., 2020). As a child moves from these entitlement programs and transition to adulthood, the transition plan is intended to guide young adults and their families through this important milestone (Locke et al., 2015). Holz et al. (2006) provided a transitioning booklet for parents that delineate the transition plan from the IEP and includes employment goals and a timeline, residential options, vocational readiness training, post-secondary education opportunities, collaboration with state and private agencies, and community goals to improve activities of daily living. The booklet classifies entitlement programs that are included in the IDEA regulations when a child with a disability is under 16 years and describes protections in civil rights and discrimination law as the child ages out of the high school at 21 years (Holz et al., 2006). In addition, families that identify with a strength-based approach to adult transitioning versus a deficit that cannot be changed, support an individualized and specialized approach to assimilating to adult living (Thompson et al., 2018). Individualized approaches to transition planning, pre-employment training, social skills training, and college preparation all improve prospects to meet successful outcomes (Hendrickson et al., 2017; Shattuck et al., 2020). Based on the results of the literature review on transition planning, there is a need to provide early and ongoing planning for students with ASD that focuses on strength-based approaches.

ASD and Mainstreaming

The literature includes varied results of the effect of IDEA regarding the efficacy, inclusion and mainstreaming, and special education programming and transitioning for children with all types of developmental disabilities (Agran et al., 2017; Carrington et al., 2016; Fisher et al., 2020; Kurth et al., 2020; Papay et al., 2018; Pellicano et al., 2018). Concurrently, over the past decade there has been an increase in the amount and varied severity of ASD students participating in specialized education, prompting a shift in research designed to identify successful interventions, student outcomes, and teacher effectiveness. (Keshav et al., 2018; Love et al., 2019; Love et al., 2020; Sobeck & Robertson, 2019; Sugita, 2017; Tekin-Iftar et al., 2017). In addition, there is current researchers who focused on how the “Race to the Top”, which is a nation-wide educational initiative providing federal funds to school districts that increase academic performance and improve core standards, may negatively affect specialized and individualized programming that is at the heart of inclusion (Deas, 2018). Bicehouse and Faieta (2017) emphasized how valuing high academic achievement through standardization contradicts the basic foundations of IDEA which stress inclusion through child-centered, inclusive, acceptance of diversity. In addition, transition planning occurs at a lower rate in secondary school for those with ASD compared with other disabilities, students with ASD do not appear to know what opportunities are available, and they report that they are not a part of transitioning conversations (Chandroo et al., 2018; Chandroo et al., 2020; Hendrickson et al., 2017).

Mainstreaming of children with disabilities can produce associated challenges, especially for those with ASD who have specialized needs (Wood, 2019). Larcombe et al. (2019) identified many factors affecting successful mainstreaming that include class size, individual social/behavioral characteristics, availability of teacher assistants, and peer understanding and exposure to others with ASD. Social isolation in mainstream classrooms is associated with peer rejection and lack of reciprocal companionship, directly affecting successful integration into the classroom (Howard et al., 2019). Negative mainstreaming experiences may result in children with ASD being removed from the inclusive environment and placed in specialized classrooms or other isolated educational setting (Larcombe et al., 2019). Because students with high functioning ASD are more apt to be included in mainstreaming, they are more susceptible to feelings of social isolation, anxiety, and stress (Wigham et al., 2017). Wood (2019) found that inclusion in school and other activities for students with ASD is poor, yet, embracing their natural tendency to focus on repetition and specific interests can produce success in creative thinking and success in the overall school experience. Further, transition planning from primary to secondary education is often unsuccessful due to demands in skills needed to follow a timetable, handle larger social crowds, intellectual challenges, and emotional demands (Mandy et al., 2016). In addition, schools must consider the parent perspectives in the collaboration process of inclusion. Falkmer et al. (2015)

identified that parents value schools that focus on inclusion activities, peer development, bullying prevention, and access to support staff. From a societal standpoint, the authors also found that parents with children diagnosed with ASD want strong legislation and policy implementation regarding inclusion regulation (Falkmer et al., 2015). Finally, the literature results on mainstreaming indicate mainly negative effects on ASD children, yet parent collaboration and comprehensive transition planning appear to improve academic success (Zanazzi, 2018).

Marginalization and Bullying

Marginalization occurs in society at many levels and for people with ASD that are attempting to develop into independent members of society, it becomes more prominent (Broady et al., 2017). Niles and Monaco (2019) note the academic trend in schools where post-secondary opportunities are not realized despite children with ASD often doing better academically than their peers without ASD. One factor appears to be the belief of practitioners and teachers in secondary school, who are most often white and female, assuming ASD is a diagnosis, a disability that produces only deficits, and a personal tragedy (Niles & Monaco, 2019). Broady et al. (2017) found that stigmatization continues to be prevalent in schools and communities, felt by both parents and their children with ASD. Attitudes toward ASD in the school setting by TD peers does improve as children get older but there continues to be a negative attitude toward students with ASD well into later high school years (Aube et al., 2020).

In addition, school-age children with ASD are more prone to school bullying than there typically developing (TD) peers (Maiano et al., 2016). As victimization has increased, often due to social challenges and peer conflict, bullying has been shown to occur more often in general or mixed group school settings as mainstreaming continues to be accepted practice (Maiano et al., 2016). In addition, Tonnsen and Hahn (2016) found that TD students socially exclude peers with ASD and have negative attitudes and beliefs if they have no previous exposure to ASD, do not see the student with ASD as popular, or are older and male in the school setting. Eroglu and Kilic (2020) found that students with ASD and other disabilities experience verbal and emotional bullying at similar rates and is typically perpetrated by their male peers, with an increase in bullying based on the severity of ASD. Students with ASD appear to be more vulnerable to bullying victimization because of social impairments associated with lack of communication skills, limited social network, and relationship development challenges (Eroglu & Kilic, 2020). Therefore, it appears important for all stakeholders to understand how prevalent bullying occurs in school for those with ASD and to work toward protecting those with ASD and other disabilities in the educational and social environment.

ASD and Adult Transitioning

Researchers have addressed the effects of a large amount of young adults with ASD entering adulthood, citing the enormous financial cost rising to billions of dollars due to the continued dependency of welfare, health cost, and residential care as this population reaches adult age (Hedley et al., 2017; Howlin & Magiati, 2017; Scott et al., 2017; Scott et al, 2019). In response to the growing numbers of people with ASD entering college and the workforce, researchers indicated the push to meet the needs of these individuals through specialized approaches (Chan et al., 2018). Throughout the literature review on adult transitioning, researchers focused on findings associated with outcomes in secondary and post-secondary education, pre employment and competitive employment, and social skill training applied to community inclusion and integration (see Accardo et al., 2019; Chan et al., 2018; Kuder & Accardo, 2018; Lorenz et al., 2016; Nord et al., 2016). Despite the surge in needs of young adult's access to specialized education and community-based development and supports, young adults with ASD transitioning to adulthood continue to have poor outcomes in securing competitive employment, developing, and maintaining peer relationships, and accessing post-secondary education (Baker-Ericzen et al., 2018; Chen et al., 2018; Shattuck et al., 2020). It is clear from the literature that securing independence in employment, social relationships, jobs, familial needs, and financial security continues to require more investigation (Shattuck et al., 2020).

Further, predicting outcomes for this population as they enter adulthood is varied in the literature and contradictory in how it should be studied and how disparities are measured (see Eilenberg et al., 2019; Heath et al., 2017; Pallathra et al., 2019; Shattuck et al., 2018). Bush and Tesse (2017) identified that choice-making is a predictor of accessing and maintaining competitive employment for people with various developmental disabilities. In other words, individuals who have varied choices other than employment in a facility setting or a sheltered workshop have better employment outcomes (Bush & Tesse, 2017). In addition, social isolation beyond the family unit that occurs during transitioning for young adults with ASD after high school can produce negative effects (Cage et al., 2018; Lounds-Taylor et al., 2017). Loss of the social network includes lack of exposure to friends, mentors, coaches, community access activities and service providers (McGee Hassrick et al., 2020). McGee Hassrick et al. (2020) described a “service-cliff” when disruption occurs from losing eligibility and access to programs and services that were previously provided at the secondary level. Lounds-Taylor et al. (2017) identified that structured social activities significantly decline once a child transitions to adulthood, indicating a lack of exposure to opportunities to gain inclusion in relationships and friendships at the community level.

Further, those with ASD experience mental health issues at a higher rate than typically developing (TD) peers (Cage et al., 2018). Social isolation and lack of opportunities for adults with ASD often lead to mental health issues that may include depression, anxiety, social anxiety disorder (Keller et al., 2020). Zimmerman et al. (2020) explained mental health challenges in terms of executive functioning and found that symptoms of anxiety occurred at lower rates when individuals with ASD had social inference skills and understood social content. Keller et al. (2020) differentiated childhood ASD from adults with ASD, noting the emergence of a dual diagnosis of mental health issues that are exacerbated by lack of meaningful activity and social isolation. Further, depressive symptoms are often linked to job loss, distressing situations, and quality of life measures (Park et al., 2019). Because a large portion of young adults with ASD experience heightened levels of stress and anxiety, cognitive behavioral therapy can be affective to curb social anxiety (Ung et al., 2015). Finally, Camm-Crosbie et al. (2019) emphasized the need for individual treatment, expertise to treat a differential diagnosis of ASD and mental health issues, and an understanding how important access to treatment and support can thwart more serious symptomology such as suicide attempts. Therefore, it appears that early identification of mental health issues and interventions to improve social and emotional connections are paramount to people with ASD, particularly for transitioning adults.

In addition, initiating and maintaining intimate relationships may be a challenge as young adult's transition to independence (Strunz et al., 2017). Challenges may be associated with the lack of social engagement skills such as sustained eye contact, emotional reciprocity, lack of communication skills, and misinterpretation of social cues and behavior (Strunz et al., 2017). During transitioning, young adults with ASD either have or want to experience romantic relationships and friendships with the opposite or the same gender, as is the case more often with females with ASD (Dewinter et al., 2017). Strunz et al. (2017) identified factors associated with relationship satisfaction that include high satisfaction levels when both partners have ASD versus neurotypical peers, not having experience with friendship skill development, level of self-absorption, and level of sensory sensitivities and emotional dysregulation. Based on this research, it appears that there is a strong need to engage in intimate relationships, yet those with ASD may not have social skills or emotional regulation to initiate or maintain a relationship.

ASD and Postsecondary Education

There is a growing number of young adults with ASD entering college, with graduation rates lower than the standard average (Jackson et al., 2018). Although college education appears to improve adult transitioning for those with ASD, traditional college approaches do not address many specialized needs (Hendrickson et al., 2017). Many students with ASD may have impairments in executive functioning associated with problem solving and may struggle with concentration in class, focusing on independent instruction, negotiating a large campus with multiple class assignments, and as a result, may experience depression, anxiety, and adjustment issues (Dallas et al., 2015). It appears from the existing research that higher income households plays a factor in greater postsecondary education (PSE), severity of ASD symptoms interferes with successful PSE, and lack of access based on demographics are all indicators for PSE engagement (Taylor et al., 2015).

In addition, self-determination appears to be a predictor for success in higher education for people with ID/DD. Shogen et al. (2018) found that self- determination was supported through inclusion opportunities such as social/communication based programs, technology to augment social communication, resident life activities and residencies that are accommodating, and social activities with people who do not have a disability. Further, postsecondary education increases the ability of young adults with ASD to achieve competitive employment after graduation (Whittenburg et al., 2019). Kuder and Accardo (2017) described the unique needs of young adults with ASD entering college and identified accommodations ranging from nonacademic social communication training and cognitive behavioral interventions to academic transitioning programs designed to prepare the young adult with ASD and their families individualized supports through the college journey. Moreover, it appears that peer mentoring participation in college improves both the academic needs and social supports required to address challenges for people with intellectual disabilities/Intellectual disabilities (ID/DD) (Griffin et al., 2016). Zeedyk et al. (2016) presented information on students with high functioning ASD who attend college and found that it is necessary to have faculty supports, specialized living accommodations, and an emphasis on social supports and academic accommodations. Ashbaugh et al. (2017) study focused on factors associated with students who experience social isolation in college and found that structured social programs and interaction that includes peer mentoring, weekly meetings, and planned social activities improved academic performance and satisfaction rates. Social isolation may be more prevalent when there is a lack of exposure or knowledge of ASD on any given campus setting (Ashbaugh et al., 2017). Further, White et al. (2019) found that students had reported negative attitudes towards those on campus with ASD, even with those who participated in autism training. This was consistent with Gibbons et al. (2015), who reported that faculty even more than peers were unsure about inclusion on college campuses and acceptance for specialized programs was associated with campus education and previous personal exposure to ASD.

It is no wonder that students with ASD are more prone to social isolation in response to segregation on college campuses (White et al., 2019). Hendrickson et al. (2017) explained how an “autism friendly” campus which is defined as college programming that focuses on individualized planning, ASD education, and awareness and empowerment supports, may increase success during the first fragile six months when the student with ASD is transitioning to postsecondary environments. This is hopeful research for those with ASD who are more likely to experience and require treatment for stress, depression, social isolation, and anxiety during the college transition (Hendrickson et al., 2017; Rai et al., 2018). Despite the lack of consistent transition planning due to inadequate resources, inappropriate goals, and unreliable implementation cited by Snell-Rood et al. (2020), evidence-based research predictors such as transition planning and individualized programming offers promising solutions to improve successful academic and social college outcomes. Bell et al. (2017) described how transition planning for those with ASD must begin early, be emphasized by student skills and not limitations, and to focus on interpersonal skill acquisition in varied social environments. In addition, career and life planning awareness while still in high school that consists of identifying modifications in school and work environments are necessary transition planning components (Tullis & Seaman-Tullis, 2019). It will also be important that schools understand that parents and students appear to control the trajectory of activities occurring in the transition phase. Ruble et al. (2019) emphasized the need for coaching supports for the family during multiple sessions to improve post transition outcomes.

Yet, there are promising opportunities for colleges and universities to support access and retention of students with ASD. Smulsky et al. (2015) identified the need for college faculty to be educated on approaches and interventions needed to mainstream ASD students, and how campus services should focus on the social modeling and inclusion on college campuses. Grant money at the cost of 11 million from the Department of Education was awarded to over two dozen higher education institutions to develop and maintain transition programming and services for students with intellectual disabilities and ASD (Smulsky et al., 2015). There appears to be baseline transition services for some students who enroll at most colleges in the US. Yet, Brown and Coombs (2016) found that it is rare that college transition programs supported through disability services on campuses include individualized supports specific to functional limitations for students with ASD. Because some students with ASD do not self-identify as autistic in college and do not access ASD specific supports and programs, some institutions have broadened their support program to embrace neurodiversity to decrease the stigma associated ASD (Gillespie-Lynch et al., 2017).

ASD and Competitive Employment

Researchers have provided a vast amount of information regarding the under-representation of those with ASD engaging in competitive employment (Anderson et al., 2017; Chen et al, 2018; Shattuck et al., 2020; Sosnowy et al., 2018; Taylor et al., 2015). People with ASD are less likely to participate in competitive employment and, if they are successful accessing employment, are not able to maintain employment over time (Taylor et al., 2015). In addition, Taylor et al. (2015) found that those with ASD with an average IQ are more likely to be successful in the employment environment compared to those with ASD and an intellectual disability (ID). Lorenz et al. (2016) examined employment needs of people with ASD and found that it is necessary to customize services to prepare for employment, match jobs appropriate for individuals, and individualize ongoing supports in the workplace. Chen et al. (2018) examined variables associated with positive outcomes for employment including higher family income, social maternal networks, independent skill acquisition, managing personal care needs, and living in a highly populated area. It appears from the literature that parents play an important role to help their child meet and be exposed to these variables. In addition, Southward and Kyzar (2017) identified predictors of successful employment that include job skills training, having a job in secondary school, IEPs focusing on competitive employment, graduating from high school, participating in college, and being self-determined.

It appears from the literature that self-determination is necessary for both secondary and post-secondary education and employment success (Chou et al., 2017; Oswald et al., 2018; Shogren et al., 2018). Further, Wehman et al. (2017) found that participation in preemployment skill training that included behavioral supports improved accessing and maintaining competitive employment for students with ASD in high school. It appears from the literature that adults who are on the higher spectrum of the disorder respond well to technology aided interventions in the workplace and have better outcomes maintaining competitive employment (Walsh et al., 2017). Yet, Nord et al. (2016) found that those with ASD are not accessing supported employment programs that include behavioral supports and accommodations and are not participating in competitive employment at the same rate as others with a disability. In addition, Westbrook et al. (2015) had shown that employer lack of exposure to ASD and economic conditions do affect access to competitive employment, but successful outcomes are associated with individualizing job placement and behavioral supports to maintaining employment over time. Sung et al. (2015) noted an emphasis on employment transition services for those with disabilities experiencing challenges with barriers, citing the 2014 Workforce Innovation and Opportunity Act (WIOA), which was implemented through the US

Department of Health, provides grants for stakeholders providing supports and access to employment. The WIOA requires vocational rehabilitation programs that work with children with ASD to work closely with school transitioning. Yet, the schools are largely not including these vocational programs in the planning process for transitioning employment (see Sung et al., 2015).

ASD and Parenting

Many of these research studies raise new questions about access, resources, and the burdens faced by parents when supports and funding are not available in their area. In contradiction, most studies addressing parents of children with ASD focus on the issue of stress, burnout, and how parents navigate various issues all through childhood, adolescents and during their child's transition to adulthood (Cachia et al., 2016; Karst et al., 2015; Robinson et al., 2018; Rodriguez et al., 2019; Siu et al., 2019: Stewart et al., 2017; van Esch et al., 2018; Yorke et al., 2018;). More currently, Zhou et al. (2018) examined the effects of family function in relation to affiliated stigma or the process of internalizing stigma that their child experiences. The authors found that care givers who experience affiliated stigma have higher depression levels, feel shame, and may be a predictor of psychological problems (Zhou et al., 2018). Further, it appears that caregiver strain may differ across the lifespan of the child with ASD and is dependent on if there is accessibility of services, personal family coping styles, and internal and external triggers for strain (Shivers et al., 2017).

Parents and caregivers who have children with ASD are challenged in various ways throughout their child's life. During many milestones including adult transitioning, Meleady et al. (2020) identified a shift in parenting experience from a deficit-medical model focusing on the negative aspects, to a positive adaptation model (Brown et al., 2020; Garcia-Lopez et al., 2016; Iida et al., 2018; Potter, 2016; Stanford et al., 2020; Weizbard-Bartov et al., 2019). Parents with higher expectations and high self-efficacy and are engaged in pre-transitioning programming reported elevated satisfaction during adult transitioning for their child with ASD (Kirby et al., 2020). A similar article, Holmes et al. (2018) emphasized how parent expectations that are fostered through knowledge, engagement, and future planning along with youth preparation contribute to successful adult transitioning.

In the area of parenting and caregiving for children with ASD, there is a distinction in research between how parenting other disabilities is viewed as a fulfilling and rewarding experience, yet ASD parenting is wrought with stress and burdens. For example, the literature review revealed how caregivers of other developmental disabilities other than ASD are portrayed from a positive psychology model that focuses on a rewarding and gratifying caregiver experience (Burke & Heller, 2016). Burke and Heller (2016) go on to note that caregivers with children diagnosed with ASD are still characterized in the stress and burden model in the research (Ilias et al., 2018; Postorino et al., 2019; Shepard et al. 2018; Ventola et al., 2017), largely due to the lack of research supporting otherwise. What is known is that parent knowledge and parent efficacy have been identified in the literature as protective factors against the challenges, stress, and burdens associated with ASD such as their child’s behavioral difficulties (Lindsey & Barry, 2018). In addition, Ventola et al. (2017) provided comparisons between types of disabilities and how parenting styles and stressful milestones required more supports and resources to keep the family unit intact. The authors found that parent behavior and style have implications on how their children with ASD internalize and externalize interventions and approaches parents choose (Ventola et al., 2020). Ventola et al. (2020) found that maladaptive behaviors can be lessened when parents are equipped with the proper tools to respond appropriately and to recognize how their own emotional or mental state affects the success of child growth.

There is ample literature examining ASD parenting and quality of life indicators (Dardas & Ahmad, 2015; de Bruin et al., 2015; Nuske et al., 2018; Rayan & Ahmad, 2016; Vasilopoulou & Nesbit, 2016). Factors associated with lower quality of life for parents with ASD include limited social support for mothers, maladaptive behavior expressed by their child, and lack of employment (Vasilopoulou & Nesbit, 2016). Rayan and Ahmad (2016) found that mindfulness-based interventions or a non-responsive neutral response to their child's negative behavior improves parent ability to assess the situation which in turn, decreases stress and psychological discomfort. The effectiveness of mindful parenting on caregiver stress was confirmed in de Bruin et al. (2015) study that resulted in an improved quality of life, an increase in parent competence, and development of a more assertive parenting style.

Parent Education Versus Parent Instruction

Parent training or PT and parent education PE are viewed differently in the ASD literature review. Preece and Trajkovski (2017) describe PT as structured teaching associated with improving psychosocial, familial, behavioral, and academic issues that are child focused. PE is defined as parent specific education to increase information, skills, and sharing of ideas associated with the family (Preece & Trajkovski, 2017). Preece and Trajkovski (2017) indicated that often researchers will use PT and PE interchangeably when there are distinct differences. Bearss et al. (2015) recognized a distinction and found that parent training (PT) was more affective addressing their ASD child's problem behavior compared to parent education (PE) efforts. Lecavalier et al. (2017) confirmed these results indicating maladaptive behavior in children with ASD was significantly reduced when PT was used versus PE. More, Scahill et al (2016) showed overall adaptive improvement in their child's daily functioning behavior compared to parent education alone.

Yet, community-based research specific to naturalistic settings combine PE and PT without strict boundaries between the two, to elicit the largest effect of variables with a particular program or initiative (Nevil et al., 2018; Stadnick et al., 2015). For example, Stadnick et al. (2015) found that there were improvements in child-based parent training programs and education that increased parent self-efficacy to lower stress and anxiety associated with parenting children with ASD. Further, there are discrepancies in research of parent-mediated programming that suggests differences in outcomes based on parent reporting and clinician-based tools that are used to measure efficacy of a program (Nevil et al, 2018). It appears more research is necessary due to the lack of research associated with PE and PT in community-based settings that cannot control for many variables and factors associated with parent issues and child specific interventions (Stadnick et al., 2015).

ASD Parents and Stigma

Stigma has been reviewed regarding children with ASD, yet there is significant research in parent and caregiver stigma associated with caring for children with ASD (Chan & Lam, 2017; Liao et al., 2019; Papadopoulos et al., 2019; Patra & Patro, 2017). In the literature, terms for parent stigma vary and may include affiliated stigma, internalized stigma, and self-stigma (Liao et al., 2019; Patra & Patro, 2017). Chan and Lam (2017) studied how society evaluation and criticism prompts parents to self-stigmatize and then process negative mental thoughts habitually. Because psychological stress and the responses to stress affect parenting styles, it is important to mitigate self-stigmatization (Wong et al., 2016). Further, self compassion is a protective factor that decreases psychological stress associated with stigma and autism (Wong et al., 2016).

Affiliated stigma or when others are associated with the person with a disability, occurs at higher rates toward parents who have children with high severity ASD (Patra & Patro, 2019). Zuckerman et al. (2018) reported that parent stigma occurs at higher rates depending on the number of ASD in the family, nativity of the parent, unmet care needs, and ASD severity. Further increases in stress and feeling stigmatized occurs more often when parents identify the lack of family support (Lovell & Whetherell, 2019). Finally, it is important to support caregivers of children with ASD and provide acceptance to decrease affiliated stigma (Werner & Shulman, 2015). Social support for parents with children diagnosed with ASD decreases perceived discrimination and improves self-esteem (Recio et al., 2020).

ASD Parents and Relationships

Researchers indicate mixed reviews of the effect of co-parenting children with ASD (Burrell et al., 2017; Hu et al., 2019; Lashewicz et al., 2018; Sim et al., 2017). Hartley et al. (2017) found that negative effects were prevalent and associated with less couple time together, stress of responding to challenging behavioral needs, less partner closeness and interactions, and fewer positive interactions. Relationships may be affected by the ASD diagnosis causing partner stress, effects on other children in the family unit, and lack of close access to community supports (Sim et al., 2017). Brown et al. (2020) found that parent stresses is reduced, and relationship satisfaction improved when parents of children with ASD had access to education to improve coping skills, relying on one another during times of stress.

Yet, “spill over”, termed by Hartley et al. (2018), may still occur when caregiver stress and tension effects marital interactions and satisfaction. In a similar study, this phenomenon is supported in Kwok et al. (2015) who identified that mother marital satisfaction is associated with a strong partnership alliance, lower stress levels due to satisfaction with their partner, father involvement, and high self-efficacy handling their child with ASD. Yet, Harley et al. (2017) found a positive effect from the negativity of lack of engagement and cooperation during parenting and the ensuing conflict that occurs may cause couples with children with ASD to have more sensitivity to one another because they have a level of empathy from their shared experience. Regardless, it is clear from the parenting literature review that supports for children with ASD must include a comprehensive approach to include support for the family unit and the parent relationship heath (Ooi et al., 2016).

Parent Supports and ASD

Although there is little known about the effectiveness of parent-based intervention in the literature, Rutherford et al. (2019) reviewed various approaches to address parent stress and support such as meditation and relaxation, parent education, and parent support groups and found that mindfulness training and relaxation is positively correlated with lowering stress for parents raising children with ASD. Likewise, mindfulness training or the ability to slow down negative thoughts and calm your body was found to decrease psychological distress in parents (Lunsky et al., 2017). Further, Bearss et al. (2015) described the use of ASD parent training as widespread such as social and communication approaches, care coordination training, psychoeducation training, and well known, evidenced based training addressing maladaptive behaviors.

Parents that are more educated regarding ASD and have higher self-efficacy with strategies to cope with issues associated with ASD have greater satisfaction in the caregiving process (Salas et al., 2017). Self-efficacy is associated with buffering stress when individuals have an ability to access tools to understand how to approach challenging issues and recognize strengths associated with mental health and psychological well-being (Schönfeld et al., 2016). Galpin et al. (2018) studied what parents want in supports and identified that the lack of supports adds to isolation and alienation, and practitioners and teachers need to focus on family-centered, collaborative approaches that are available during times of distress. This was mirrored by Hartley and

Schultz (2015) who pointed out that parents want clinicians to use a family-center approach that includes developing close, trusting relationships, having open communication with challenging issues with child behavior, and focusing on interventions that closely match the specialized and unique needs of their child.

ASD and Mother and Father Differences

Support needs appear to be similar between mothers and fathers caring for children with ASD. Hartley and Schultz (2015) found that both parents agreed in important areas of support need and only showed differences in what they felt were unmet needs. Both parents can benefit from supports and instruction to decrease stress through coping skill development, which improves their interaction and response to their child's challenging behavior (Kiami & Goodgold, 2017). Because mothers often fill the role of the caregiver most of time, they appear to understand the needs of their children with ASD more effectively but experience stress at higher levels (Hartley & Schultz, 2015; Kiami & Goodgold, 2017; Pisula, & Porębowicz-Dörsmann, 2017; Soltanifar et al., 2015). Stress for mothers may be associated with specific unmet needs such as the lack of financial supports, the need for respite breaks from child-rearing, and the need for self-care and sleep (Kiami & Goodgold, 2017).

Yet, fathers are underrepresented in the literature. Burrell et al (2017) found that fathers experience parenting an ASD child similar to mothers, with the focus on attaining independence and community acceptance and integration and stress is experienced due to the burdens of caregiving. Differences include the tendency for fathers to limit their input regarding the needs of their child with ASD (Burrell et al., 2017). Dardas and Ahmad

(2015) described how the roles of fathers are important because their level of engagement and nurturing affects the child, spouse, and family unit. Fathers who are engaged recognize the importance of maintaining the family dynamic and may not want to disrupt the role of the mother (Burrell et al., 2017). Yet, DePape and Lindsay (2015) found that more fathers than mothers will increase their hours at work after the ASD diagnosis of their child, leaving the mothers the larger caregiver responsibilities. Many fathers may feel loss after a diagnosis of ASD and envious of those fathers with typically developing children who do not have added caregiving demands (Cheuk & Lashewicz, 2016). Still, fathers are considered attentive to their ASD child's needs and are strong supporters and advocates for individualized services (Cheuk & Lashewicz, 2016). Based on these results, fathers appear to experience parenting a child with ASD similarly to mothers.

ASD and Family Units

Relationships and family units can be affected in various ways when issues with raising their child with ASD arise. Iadarola et al. (2019) found that parents that are under-represented in communities such as Spanish speaking, rural parents with limited income, experienced stress associated with frustration in services coordination, family dysfunction, and require service providers to recognize cultural barriers to treatment. In addition, siblings affect the family dynamic for the parents and the child with ASD. McHale et al. (2016) noted that siblings often positively affect the child with ASD by providing a role model for appropriate social interaction and emotional regulation, identifying social cues and communication modeling, and teaching friendship skills. Yet siblings may add to the stress and complications to the parent caregiving process.

Siblings of children with ASD are more likely to have emotional issues associated with depression and anxiety and have behavioral difficulties (Jones et al., 2019). On the other hand, Shrivers et al. (2019) found that siblings may have a prevalence to develop helping skills learned by parents and are reported to have high levels of empathy, which may help parents care for the child with ASD.

Family unit quality of life indicators were identified in Boehm et al. (2015) who found that improved quality of life during adult transitioning was associated with less negative behavior of the child with ASD, parents with strong religious faith, and lower supports required during the milestone. More, strong partnerships between the family and teachers improves quality of life and decreased stress for caregivers (Hsiao et al., 2017). Yet, Schlebusch et al. (2017) singled out emotional well-being and found that families experienced lower levels possibly because families have less access to social networks that buffer stress and psychological discomfort. Parental adaptation training or specific instruction to handle challenges that have potential to increase anxiety, stress, and depression, has shown to improve quality of life (Bohadana et al., 2019). In addition, DeWalt et al. (2018) found that families are interested in comprehensive family-based intervention focusing on increasing community social networks, improving problem-solving skills, and training in the coordination and advocacy for their child with ASD.

Within the family unit, grandparents often augment caregiving, provide financial supports, and give respite relief for parents of children diagnosed with ASD (Hillman et al., 2016; Kahana et al., 2015; Predenville & Kinsella, 2019; Sicherman et al., 2018). Kahana et al. (2015) emphasized the importance of an intergenerational approach to raising a child with ASD that includes relief for the financial burdens associated with care and services, access to services, and adding to resilience within the family unit. Grandparent supports, especially grandmother supports appear to improve early intervention and diagnosis associated with the advocacy for ASD children (Sicherman et al., 2018). Yet, grandparents are often excluded from the services offered to parents associated with decreasing maladaptive behavior and improving coping skills associated with caregiving (Parker & Molteni, 2017). Desiningrum (2018) found that by including grandparents improves the psychological well-being of the child and the grandparent.

ASD Parenting and Financial Issues

As parents attempt to meet the needs of children with ASD transitioning to adulthood, financial burdens may impede success (Douglas et al., 2017). Depape and Lindsay (2015) identified how the financial situation changes after ASD diagnosis including the need to work longer hours or quitting their job because caregiving responsibilities had become too great. As a result of not being able to cover all the expenses required to care for their child, often parents must access loans, extract from retirement funds, or refinance mortgages (Depape & Lindsay, 2015). Grandparents often augment parent finances by putting off their retirement or using retirement funds for the needs and services of their grandchild with ASD (Hillman et al., 2016). Further, Marsack-Topolewski and Church (2019) found that quality of life, particularly for parents 50 and older, is associated with the level of caregiver financial burden that is experienced. Although, Pandey and Sharma (2018) found age of parent is not a factor in financial burden experienced. In addition, the authors identified that the level of parent education is a factor that affects the amount of financial burden experienced (Pandey & Sharma, 2018). Parents who are more educated and are empowered to access programming and services are more motivated to participate and complete parent-mediated services such as telehealth appointments (Ingersoll & Berger, 2015). These results indicate that there is added financial burden parenting a child with ASD as they attempt to transition.

ASD, Insurance, and Health Care

Douglas et al. (2017) reviewed insurance caps that were implemented for private coverage associated with assessment services, diagnosis, and treatment in the United States. Since 2014, private insurers are now required to cover diagnostic and treatment services for those with ASD (Chatterji et al., 2015). Candon et al. (2019) emphasized the need to increase policy that focuses on decreasing out-of-pocket expenses and holding insurance companies accountable. These barriers to care are widespread and include the lack of service providers and insurance coverage that was prompted by the collapse of many terms and diagnoses related to ASD and put into one category in the revised DSM-5 (Barker & Galardi, 2015). Many diagnoses were no longer recognized based on the new revision. Johnson et al. (2015) emphasized that many children would now be excluded from an ASD diagnosis based on new criteria from the DSM-5, and others with pervasive developmental disorders (PDD) and other diagnoses may no longer receive treatment and services specific to their needs. The purpose in revising the DMS-IV-TR to the more diagnostically consolidated DSM-5 was to have greater clinical consistency and specificity, yet communities, parents, and service providers were not prepared for the effect of the new classification system (Doernberg & Hollander, 2016). As a result, many parents may have children who no longer receive services due to their diagnostic category because they are not recognized as having ASD (Doernberg & Hollander, 2016).

Parents of children with ASD transitioning to adulthood must help coordinate many transition services, including the need for adult level health care for their young adult. Zablotsky et al. (2020) described health care transition (HCT) planning as a necessary requirement for healthcare providers to coordinate for seamless healthcare into adulthood, especially for those young adults with specialized needs such as autism. Although this specialized population requires more healthcare services, have more and longer stays in hospitals for inpatient needs, and have higher costs due to specialized needs, only 15-21% receive HCT planning (Zablotsky et al., 2020). Nathenson and Zabltsky (2017) found that although transition planning is needed more during adult transitioning, there is a notable decline in healthcare use and in multiple environments. On the other hand, those with ASD and depression do receive proper treatment in the healthcare system with a high level of patient satisfaction (Kuhlthau et al., 2016). Because the level of parent expectation is a predictor of successful transitioning, stakeholders such as primary healthcare providers can positively influence parents to engage in preparatory activities for their child (Holmes et al., 2018).

In the literature review, private insurance compared to publicly insurance such as Medicaid does not appear to meet the needs of families raising children with ASD (see Chatterji et al., 2015; Parish et al., 2015; Thomas et al., 2016;). Medication, dental services, and out-patient expenses are estimated as 5 times more likely when parents of children with ASD have private versus public insurers, causing immense financial burdens on the parents (Parish et al., 2015). Medicaid and some private insurance programs appear to adequately cover basic medical needs and out-patient services, yet parents who have children with ASD may be unaware of the terms in private insurance contracts (Thomas et al., 2016). Further, many private insurers, although mandated to provide ASD coverage, do not cover behavioral interventions and look to the education entitlement programs to meet this need (Catterji et al., 2015). In addition, parents may be unaware that the lack of dental care can produce serious health risks to their child with ASD and, due to employment loss and financial burdens, will not pay full price for tooth care (Wiener et al., 2016). Dental care becomes a necessity because lack of utilization of dental care is associated with children at high risk for dental problems and potential mortality for children with ASD (Wiener et al., 2016).

ASD Parents and Guardianship

Parents of children with ASD must consider options with guardianship, especially during adult transitioning, and possible alternatives when their child's autonomy may be compromised (Demer, 2018; MacLeod, 2017; Spath & Jongsma, 2020). Autonomy in life choices for those with ASD may be compromised due to interference from others to make decisions, parent behavior that limits choices of their children, and inaccurate expectations and assumptions about capacity to make sound judgments (Spath & Jongsma, 2020). Individuals with guardians may lose their basic rights to possess a driver license, marry, vote, or be engaged in legal contracts (MacLeod, 2017). Yet, parents often enter in guardianship arrangements because they believe protections are required and have good intentions toward their child’s well-being (MacLeod, 2017). To complicate matters, guardianship and partial guardianship in the US can be a confusing process because there is limited government oversight, unnecessary restrictions may be implemented, there may conflict of interest in areas such as fiduciary access, and there is limited federal and state oversight with guardianship appointments (Keller et al., 2020).

When deciding on guardianship, parents and other stakeholders are encouraged to reinforce decision-making skills, independence, adaptive skill development and regularly access strengths and limitations required for independent living (MacLeod, 2017). MacLeod (2017) listed approaches to improve independence that include an inclusive educational experience in primary and secondary school, person centered planning to explore alternatives to guardianship, peer and community networking, resource advocacy and education, and continuous transition planning. Finally, it is important for parents and other stakeholders to recognize that autonomy should not be automatically restricted do to ASD limitations but reconceived to include an interconnected approach to decision making associated with challenging issues (Spath & Jongsma, 2019).

Summary and Conclusions

An understanding of how parents with children with ASD experience their child’s transition to adulthood is the focus of this study. The review of the literature provided a broad range of information that summarized characteristics of ASD and how parenting must be individualized to meet the varied presentations of their children with ASD (Cai, 2017). Symbolic interactionism (SI) provides a foundation for recognizing that ASD presents differently and will therefore affect how parents may provide differing perceptions of the same phenomenon of adult transitioning (Totkova, 2019). SI is the theoretical framework for understanding how parents and children with ASD experience daily life experiences through interaction, assignment of meaning, and acting on that understanding (Denzin, 2016). The views of the lived experience of parents who have children transitioning with ASD will improve understanding of successes, challenges, and speak to educators, practitioners, advocacy groups, and institutions that provide necessary supports and services to parents and children with ASD. The literature review is separated into ASD and characteristics, ASD, education and transition planning, ASD and adult transitioning, ASD and post-secondary education, ASD and employment, and ASD and parenting. Because parents drive and coordinate planning and services, new perspectives can be developed to encourage better alignment between assumptions and expectations of parents and providers (Marsack & Perry, 2018).

ASD characteristics in the literature were broadly uniform across research studies and include restricted, repetitive behavior, stereotypical behavior, sensory deficits, and communication and social deficits (APA, 2016; Ashbaugh et al., 2017; Barnett et al., 2018; Bell et al., 2017; Brown & Coombs, 2016; Jackson et al., 2017; Masi et al., 2017). The literature review revealed that because of the unique presentation of various levels of symptoms that children with ASD exhibit requires parents, educators, and institutions to individualize and accommodate services and programming (Cai, 2016; Hendrickson et al., 2017; Ohl et al., 2017; Shattuck et al., 2020). The severity of symptoms particularly in communication, restrictive behavior, and maladaptive behavior plays a dominant role in academic, social, and occupational outcomes (Anderson et al., 2016; Shattuck et al., 2020).

ASD and education literature review uncovered the effect of mainstream, inclusive educational environments, negative factors associated with academic initiatives, and the lack of transition-planning at the high school level (Eapen et al., 2017; Locke et al., 2015; Papay et al., 2017). Many young adults with ASD continue to require supports and do not achieve independence, remaining with their parents long into adulthood (Bush & Tess, 2017; Hedley et al., 2017; Howard et al., 2019, McGee Hassrick et al., 2020; Scott et al., 2019). Further, the literature revealed that peoples with ASD were more prone to bullying in high school (Erogln & Kilic, 2020; Maiano et al., 2016), did not develop intimate relationships (Strunz et al., 2017) or friendships at the same rate as TD peers, and were more likely to have a mental health issue such as depression or anxiety (Cage et al., 2018; Camm-Crosbie et al., 2019; Keller et al., 2020). To improve outcomes, interventions included a focus on developing self-determination/choice-making, structuring social activities to improve human engagement (Lounds Taylor et al., 2017), decreasing sensory overload and providing expert, individualized mental health interventions (Berkovits et al., 2017; Camm-Crosbie et al., 2019).

Themes in the literature emerged in the areas of competitive employment and post-secondary education and include the limited amount of individuals with ASD accessing jobs and participating in college (Jackson et al., 2018; Taylor et al., 2017; Whittenburg et al., 2019), the need for specialized, individualize supports and accommodations based on need (Kuder & Accardo, 2017; Zeedyk et al., 2016), and the issue of cultural stigma in the workplace and institutional setting interfering with integration (Smulsky et al., 2015; White et al., 2019).

The literature on parenting children with ASD focused on the stress and burden caregivers face continuing parenting responsibilities and care coordination well into adulthood (see Cachia et al., 2016; Karst et al., 2015; Robinson et al., 2018; Rodriguez et al., 2019; Stewart et al., 2017; Siu et al., 2019: van Esch et al., 2018; Yorke et al., 2018). Yet, Burke and Heller (2016) identified that there is little research focusing on a positive model of caregiving due to the lack of information saying otherwise. Further, Kirby et al. (2020) found that parents are more satisfied when they have higher expectations for their child, high efficacy, have a strong knowledge base, and are engaged in the process of adult transitioning. In addition, Lindsay and Barry (2018) identified protective factors against stress and burnout and confirmed that knowledge and self-efficacy improved parenting outcomes.

Although there was literature that focused on how parents deal with the adult transition period, including the continued care and coordination of activities, research was limited to the negative effect caregiving produced for the parent and the child (Brown et al., 2020; Potter, 2016). There was little on the qualitative lived daily experience of parents with children with ASD who are transitioning to adulthood. Therefore, there is a need for this study to gain rich information that can elevate knowledge during the fragile milestone of adult transitioning for children with ASD from the parent perspective. After reviewing the literature for this study, I have adopted a phenomenological design and will use open-ended interviews as my method to gain the parent perspective of their child’s adult transitioning process. In chapter 3, I will give detailed information about the interview process that is guided by an interview guide, sample population, role of the researcher, ethical issues, and instruments that are geared to collect specific, individualized data from the parent lived experience.

Chapter 3: Research Method

The purpose of this qualitative phenomenological study was to explore parents lived experience transitioning their child with ASD to adulthood to address the problem of parents who must continue to support and coordinate all areas of their child’s life well into adulthood (see Spiers, 2015; Paradiz et al., 2017). In this chapter, I include the study methodology and design, the role of the researcher and researcher ethics considerations, the population criterion and rationale, procedures to identify participants, sample strategy and size, procedures for recruitment, study instruments, data collection and qualitative data analysis. Chapter 3 will also address confirmability, credibility, transferability, and dependability of the study.

Research Design and Rationale

The qualitative design of the study that best aligned with my research goal is phenomenological. A phenomenological approach was appropriate because the process attempted to explore the life story, beliefs, experiences, and constructs and assigns meaning to the phenomenon by creating common themes (see Saldana, 2015). The process allowed for me to identify the lived experience of parents who have specific experience and knowledge of the adult transitioning process of their children with ASD and aligns with SI theory. A phenomenological approach requires an emergent design that allows for participants to describe their lived experience, moments, stories, anecdotal accounts, so the researcher can capture the essential, consistent, shared structures of the phenomenon (Hopkins et al., 2017). Interviews with open-ended questions were used as a method to gather data. This method was appropriate because it allowed for individual and contextual responses that are unique to the participant, eliciting the most in-depth and rich information. My research question speaks to the need to find the essence of what the experience means to these individuals. Seidman (2012) noted that interviewing as a form of data gathering is time consuming and costly, but necessary if the true meaning is to be identified in phenomenological research.

Role of the Researcher

The role of the researcher was important when applying a phenomenological approach. The phenomenological approach includes the researcher as the primary instrument and required my ability to understand my own positionality. The focus had to move between the general essence and the idiographic experiences of the parents, bracketing and reflexivity must be applied to balance preunderstandings of the phenomenon, and special care must be taken to write and articulate the issues (see Hopkins et al., 2017). In qualitative research the researcher is the primary data collection instrument (Patton, 2015). Biases must be addressed during all parts of the writing process.

To address the researcher positionality as the primary instrument of the study, a 3-1 phenomenological framework was employed. Hopkins et al. (2017) described three dimensions that run on a continuum during analytical writing; bracketing (preunderstandings) or reduction of biases and subjective views/reflexivity or negotiation of what information is used, the general (essence) to the particular (idiographic), and description (what and how the phenomenon is experienced) versus interpretation (to find meaning). Because all three of these dimensions run on a continuum, it allowed for flexibility in negotiating what is considered most important, mitigate bias, will guide what information needs to be included, and control for researcher positionality (Hopkins et al. 2017).

Further, research credibility associated with qualitative inquiry must include strategies to prove dependability, transferability, and confirmability that validate the trustworthiness of the reconstructed research results (Morse, 2015). To create credibility, I provided member checks for participants throughout the interview process, once interviews were transcribed, and after the results were synthesized. Also, peer-debriefing by my chair and committee were paramount to the accuracies of my interpretations and processes. Triangulation was achieved through peer debriefing from other researchers, participants, and outside expert auditors and review boards to confirm or question accuracy (see Morse, 2015).

I provided an audit trail to identify my decision choices and I spent prolonged time with the participants reviewing and re-reviewing the data. Patton (2015) stated that an inquiry audit can provide dependability and confirmability when triangulated with other review approaches. Further, Morse (2015) described how thick description is accomplished by spending a prolonged amount of time with the participants to achieve authentic, natural responses. Finally, a reflexive journal was used throughout the process to examine my own beliefs, decisions, and how or if it influenced the research process.

Methodology

Population

The initial recruitment and data collection process included partnering with an organization who provides support for people with ASD and their families. However, after weeks of reaching out to like agencies with no success, recruitment changed to snowball sampling and through a Facebook flyer. The snowball sampling approach was appropriate because there was a need to include only individuals who have experienced a phenomenon who meet set criteria, who are the experts on the phenomenon, and who are hard to find. The process included participants finding other participants that meet the criteria. Because this study required a need to access available and motivated participants who are parents experiencing adult transitioning of their child with ASD, and who have the expertise to understand the phenomenon, snowball sampling was aligned with the approach.

The participant inclusion criteria were comprised of parents of children with a formal diagnosis of ASD, ages 18-26, and have completed the transition to adulthood. The participants were vetted and exclude all parents who have self-diagnosed young adult children, parents of children with ASD who have not lived at home, and parents who choose not to participate in the study during recruitment. Proof of diagnosis of ASD by a licensed professional based on the DSM 5 (American Psychiatric Association, 2013) diagnostic criteria, and living at home were required to participate in the study. Requests for these documents were part of the recruitment email. The inclusion criteria were directly associated with the population, the process of transitioning to adulthood, and the characteristics of the parents in the sample. Inclusion and exclusion characteristics and criteria allow a researcher to purposefully select the individuals, setting, event, and processes within the parameters of the research question (Maxwell, 2012). Ten participants who met the criteria and provided documentation of a formal diagnosis and child residency agreed to participate in my study. I contacted the volunteers through email and phone to discuss their availability for interviews.

Sample Size

I initially had an intended sample size of eight to 12 participants. Mason (2010) indicated that phenomenological studies are generally between five and 25, but no less than six. The number of participants was chosen because it appeared to be a feasible group to recruit and interview within a reasonable time with only one researcher. Although many experts rely on saturation or when there is no more new information to gather to identify sample number, Guest et al. (2006) stated that there are no hard guidelines to identify the right number of a sample prior to starting the research and that the process of saturation occurs during the data collection process. On the other hand, Mason (2012) differentiated the needs of Ph.D. researchers who are often required to confirm sample amount and justification prior to beginning the research. This small size included parents who met the inclusion criteria and were considered to have the most amount of rich information and could have the greatest effect on the study. The initial sample size decreased as saturation was reached with 10 interviews in the coding process and when there was no new information captured.

Procedures

The procedures included informed consent confirmation and IRB approval prior to the start of the process. One on one interviews with parents who have children with ASD transitioning to adulthood were conducted by phone. All participants were contacted by email or phone to confirm a time and to answer any questions they may have about the process. The interviews occurred at a time that was convenient for the participant and in their own setting of choice. The interviews included questions that were open-ended and emergent, requiring changes and additions as each interview progressed. The interview guide (Appendix A) was used for all interviews and consisted of 10 questions to answer my research question. Interview guidelines are necessary because they provide a standard to increase the amount of rich, relevant, and long answers from the participants, while consistently circling back to the main assumptions of the interview to improve quality and trustworthiness of the research (Roulston, 2010). The phenomenological terms such as descriptions, perceptions, their view of the parent experience concerning all the above areas, what was their own meaning of experiencing transitioning, and what was their specific story, was included in the interview questions. I conducted each interview, journaling and completing field notes and memos throughout the process.

The questions were neutral, open-ended, congruent with the level of education and understanding of the participants and were changed as needed, and began with probing questions, main areas, and expansion of continued discussion based on the participants responses (see Saldana, 2015). Multiple questions were not asked together and there were no leading questions to force a respondent to answer in a certain way. In addition, I provided an introduction and closure statement in the interview guide in the form of a script, so I was prepared beforehand to describe all the components of the interview, consent process, and interview expectations, ending each interview with assurances regarding the handling of data, confidentiality, study results, and to answer any questions generated by the interview process.

Data Analysis Plan

Thematic analysis was used to analyze data generated from the interviews and researcher notes. Thematic analysis is appropriate because the raw data will unfold and provide patterns identified through codes, categories, and themes which will assign meaning to the daily experiences (Saldana, 2015). Thematic analysis is appropriate for phenomenological approaches because the process attempts to explore the life story, beliefs, experiences, and constructs and assigns meaning to the phenomenon by creating common themes (Saldana, 2015). Thematic analysis provided credibility to the research because it is an established method applied to phenomenological frameworks. Research credibility refers to the plausibility of the study and is accomplished by creating reliability, replicability, accuracy, and consistency (Tracy, 2010). In addition, dependability and confirmability was strengthened through an external expert versed in phenomenological design and thematic analysis who will audit the research data, memos, journals, and analysis results. This provided a layer of transparency to the analysis process.

Issues of Trustworthiness

Credibility

Research credibility associated with qualitative inquiry must include strategies to prove dependability, transferability, and confirmability that validate the trustworthiness of the reconstructed research results (Morse, 2015). To create credibility, I provided prolonged engagement and member checks with participants throughout the interview process, once interviews were transcribed, during data analysis, and after the results were synthesized. Korstjens and Mosher (2018) emphasized the importance of developing and sustaining relationships with participants and the data collected to improve trust and authentic responses, establish a familiarity with the context to elicit rich data, and to strengthen the interpretation of the data. Further, peer-debriefing by my chair and committee was paramount to the accuracies of my interpretations and processes. Transferability was achieved through thick description of the data specific to the participants and their contextual experience (Korstjens & Mosher, 2018). Triangulation was achieved through peer debriefing from other researchers, participants, and outside expert auditors and review boards to confirm or question accuracy and interpretation (Morse, 2015).

Transferability

For the purpose of this study, my intent was to access information from a small group of participants to gain a rich description of parents who are transitioning their child with ASD to adulthood. Choosing such a small pool of participants may limit transferability to other studies but is necessary to achieve a qualitative understanding of the phenomenon (Guest et al., 2010). To improve transferability, I documented the research process to allow researchers to accurately replicate my results. Further, a reflexive journal was used throughout the process to examine my own beliefs, decisions, and how or if it influenced the research process.

Dependability

Dependability provides a traceable way for the reader to understand how steps were achieved, and how certain conclusions were reached (Nowell et al., 2017). This research process included IBR approval of an interview guide and questions, a trail of notes, memos, and data. Audit trails provided confirmability and dependability through a transparent documented approach describing how and why decisions are made and how data is understood (Korstjens & Moeher, 2018). In addition, participants reviewed their transcripts for accuracy and to validate or revise the transcription.

Confirmability

Qualitative research must reach confirmability when all components of credibility, transferability, and dependability are proven within the research process (Nowell et al., 2017). A transcription service was used to provide neutrality with raw data analysis. Researcher bias was recognized and addressed through transparent documentation prior to the data being collected, during the interview process and raw data collection through notes and journaling, and peer review of conclusions and interpretation of data. Insight into researcher bias and committing to an iterative process provides rigor to qualitative research necessary to achieve trustworthiness (Johnson et al., 2020).

Ethical Issues

The researcher must include safeguards not to cause harm to all participants and stakeholders involved in the research study. Rubin and Rubin (2012) emphasized respect and honesty, do not harm, exploit, or pressure, and follow established IRB regulations. Exploitation can occur in many forms. Seidman, (2006) stated that there is an inherent imbalance of power between the researcher and interviewee because the researcher may be perceived as exploiting the participant for scholarly gain. I provided all participants with informed consent, the sample selection process will follow IRB guidelines, and I was vigilant through the entire research process when potential ethical dilemmas surface. Cypress (2018) moved the ethical issue forward by considering where the interview will take place, protecting participant consent and rights, having a strategy for sampling appropriate for the research, planning how the information is collected, and how the information is disseminated. Information was destroyed for all participants that start the process of interviews but chooses not to continue in the study. Confidentiality of all participants was maintained. Real names were not used, and the transcriptions and data were electronically secured through encrypted password access. Data will be destroyed at the end of the research process.

Summary

In this chapter, I provided an in-depth description of research design and methodology, participant considerations and sampling, instruments, role of the researcher and ethical considerations, data collection and analysis procedure, and ways to address trustworthiness. In this qualitative phenomenological study, I attempted to gain a deeper understanding of parents raising children with ASD who are transitioning to adulthood. This qualitative phenomenological approach was appropriate because the aim is to gain rich and context specific information on the daily lived experiences of parents with children with ASD entering adulthood. I reviewed thematic analysis and the features of identifying codes and larger shared themes among participants. In chapter 4 and 5 analyzed the data and findings and provided recommendations for future research.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to gain insight into the lived experiences of parents with children with ASD transitioning to adulthood to address the barriers to successful adult independence for young adults with ASD (see Shattuck et al., 2020). In this section, I present the data collected through in-depth interviews of 10 parents who are transitioning their child with ASD to adulthood. The interviews reached saturation after the 10th interview was completed. In addition, I present information regarding data collection, analysis, and managing data. The study was driven by the following research question:

RQ: What are the lived experiences of parents with children with ASD during their child's transition to adulthood?

Throughout this chapter, I have provided the established themes that were guided by the research question. Direct quotes of the parents were provided to describe the specific experiences in the context of the shared phenomenon.

Study Setting and Participant Characteristics

I received approval from Walden University IRB to begin conducting the research. IRB approval number is 04-07-21-0731463. This chapter provides findings based on the lived experiences of 10 parents who have children with ASD transitioning to adulthood. Participants for this study were recruited through purposeful snowball sampling and a Facebook flyer. All participants signed informed consent forms and had no questions regarding consent or participation concerns. All participants agreed to an audio tape and transcription of their phone call. All participants were asked 10 open-ended interview questions and other questions were asked for clarity or expansion of individual responses of participants (Appendix A). All participants met criteria for the study. Demographics include three fathers and seven mothers with children that were 18-26 years old at the time of the interviews. All 10 participants had children 18-26 years old who had a diagnosis of autism, resided in the parent home, and were at different stages of the transitioning process.

Data Collection

The initial recruitment and data collection process included partnering with an organization who provides support for people with ASD and their families. However, after weeks of reaching out to like agencies with no success, recruitment changed to snowball sampling and through a Facebook flyer. Within three weeks, 10 parents agreed to participate in the study. All participants called or texted the researcher and shared an email address. All consent forms were sent to the participant email address. All consent forms were signed by emailing by saying that they consent and there were no additional questions regarding participation. Once consent was received, phone calls were scheduled based on participant availability.

I asked 10 participants open-ended interview questions about what it is like to transition their child with ASD to adulthood. Before the questions were asked, all participants were reminded that all information gathered would remain confidential and that the participant can stop the interview at any time. All participants were asked to find a private area for the interview, free of distraction. Each interview lasted between 30 and

60 minutes. After reviewing the data collected, saturation was reached at 10 interviews. According to Guest et al. (2006) saturation is accomplished when no new information can be gathered about the phenomenon. Therefore, data collection was complete and able to be analyzed.

Evidence of Trustworthiness

Credibility

Research credibility associated with qualitative inquiry must include strategies to prove dependability, transferability, and confirmability that validate the trustworthiness of the reconstructed research results (Morse, 2015). I created credibility by developing rapport with participants through prolonged engagement with my initial contact, email correspondents, follow up calls, and extensive, in-depth interviews. Korstjens and Mosher (2018) emphasized the importance of developing and sustaining relationships with participants and the data collected to improve trust and authentic responses, establish a familiarity with the context to elicit rich data, and to strengthen the interpretation of the data. Member checking was offered through participant review of the original transcript prior to data analysis. Peer-debriefing occurred through my chair and committee review and audit of my data collection process and analysis.

Transferability

A small sample was purposely used to extract rich, in-depth information from parents who have first-hand experience transitioning their child with ASD to adulthood. Choosing such a small pool of participants may limit transferability to other studies but is necessary to achieve a qualitative, in-depth understanding of the phenomenon (Guest et al., 2010). I improved transferability by detailing all steps of recruitment, informed consent, data collection, and data analysis. A notebook was used to reflect on each step in the process to identify preconceived attitudes or biases.

Dependability

Dependability provides a traceable way for the reader to understand how steps were achieved, and how certain conclusions were reached (Nowell et al., 2017). The research process included IRB approval of an interview guide and questions, ethical training and completion certificate, documentation, and approval of all steps to recruit, and collect data, and a thorough process for analysis. All memos associated with data collection and journaling were saved as part of the study process. This audit trail provided a transparent documented approach describing how and why decisions are made and how data is understood (Korstjens & Moeher, 2018).

Confirmability

Qualitative research must reach confirmability when all components of credibility, transferability, and dependability are proven within the research process (Nowell et al., 2017). Otter was used to audio tape the phone interviews, which also transcribed and coded the interviews. Therefore, NVivo was not necessary at this step. Researcher bias was addressed through documentation prior to the data being collected, during the interview process and raw data collection through notes and journaling, and peer review of conclusions and interpretation of data. Insight into researcher bias and committing to an iterative process provides rigor to qualitative research necessary to achieve trustworthiness (Johnson et al., 2020).

Data Analysis

All recordings of interviews were automatically transcribed to text by the Otter transcription service. All transcriptions were downloaded and were password protected on a desktop. I thoroughly read all transcripts to become familiar with the data. All transcripts were reviewed for confidential information and names were redacted, assigning numbers to each participant. Thematic analysis was used to analyze data generated from the interviews and researcher notes. Thematic analysis is appropriate because the raw data will unfold and provide patterns identified through codes, categories, and themes which will assign meaning to the daily experiences (Saldana, 2015).

Codes, Categories, and Themes

I used manual codes to find initial codes and emerging categories and themes. Codes were organized based on patterns that emerged between all ten interviews. All codes corresponded with words and phrases associated with each pattern or category. Codes were grouped and refined based on repeated themes that emerged from the data. Coding data allows the researcher to organize the transcripts to identify themes that provide meaning to the information (Williams & Moser, 2019). After transcripts were coded, categories emerged which provided specific themes of shared experiences between participants. Six distinct themes materialized in the data that were associated with answering the research question: negative effects of Covid on transitioning, community, and school pre preparation of transitioning, parenting and ASD during transitioning, ASD characteristics and challenges, ASD parenting and effects on marital satisfaction, and post-transition outcomes and recommendations. All themes, categories, and codes can be found in Table 1. Example evidence can be found in Appendix B.

Theme 1: Negative Effects of Covid on Transitioning

The negative effect of Covid on transitioning was a common theme for nine out of the 10 interviews. Participants described the lack of structure, lack of community programs, college and vocational programs, and the disruption of high school activities for those students still in secondary school. Participants noted the lack of daily structure caused their children with ASD to regress in their functioning level and display increased frustration and depression. Participant 6 stated that “everything just dropped off, she’s declined, and she seems depressed.” The interview also included “she's clearly depressed, and not all days but more days than she used to be. Right, which affects her overall functioning. Yeah, just fearful.” Participant 10 described that their child had to catch back up to her previous level of functioning”.

> COVID has really put a damper on things for her. She was going to a lot of social groups and things of that nature to help her with a lot of these issues with social anxieties and things like that, and not been able to do that. We also were not fully remote from last March until this past March, days shy of an entire year. So that has really held her back some of the things that we have worked so hard for. So now, you know, getting her back up to that level is a little bit of a challenge, but she is trying really hard.

Most interviews spoke of the negative effects of isolation, lack of supports, and in skill development. They emphasized their concern for areas that they observed regression and decline.

Participants noted that services were unavailable, and activities were suspended. These issues were described by Participant 5:

> And then like I said the COVID had so that kind of put a delay on getting everything started for all that. So, he just started using the services now. He was supposed to do job training, but because COVID They could not send them out to do anything. So, he was just sitting in the classroom doing nothing. Wow. He didn't like sitting there with a mask on.

Many participants had similar experiences, explaining the lack of employment and academic opportunities that were once available pre pandemic.

Difficulties with home schooling was also noted in most interviews. Participant 5 stated,

> When he had to do the home schooling that was a little bit more difficult for him because he really didn't know how to get in there and find his own work and stuff in it... but he just wasn't very good at maneuvering through everything, because he said that they didn't really do that much on the computer at school through the Google Chrome so he didn't really know where to go to get some of the stuff

Participant 3 indicated that there were problems with her daughter's lack of focus and the lack of supports that occurred during Covid,

> She got no services being home with COVID. Her summer school program, extended school year was 45 minutes a day for just virtual and no speech, nothing. Wow, when she went back for the school year virtually, she did have speech and counseling appointments, virtually, but the whole virtual schedule was just horrendous. It did not follow the regular school day like school was supposed to start at 7:50am, but they didn't want her to log on until 815 and being late to turn the camera on for her because she was taking someone else's temperatures, got the class late, trying to follow along with it and I'm like, look. She can't take notes.

Later Participant 3 shared that she had to support her child during the day,

> Okay, so basically, I'm in school all day. Because nothing is going to happen independently, right. You're not going to turn off the screen, and she is not going to go read seven paragraphs by herself, right, and then take notes. I do not know who thought this was ever going to work. So, it was horrible. It was absolutely just horrible.

Participants described the absence of direction due to their child's lack of supports and their inability to function independently.

One participant noted that their school did not have a plan to go remote and that there was a complete halt of all education for a period,

> Terrible. I mean, the school obviously had to go remote, like all the schools went remote. So, when everything first shut down which was what in March. The school just stopped, she just quit going, you know, they're like, well we're shut

> down, but they didn't go remote, they didn't do anything and it's like, what are they gonna do so it took a while, I would say probably over a month.

Participants noted that there was a lag in any services or direction from their school systems. Noted was lack of structure in various settings due to inactivity and lack of independent direction.

Overall, most participants described negative effects of Covid with their children, who were experiencing transitioning to adulthood from many different stages. Two subthemes surfaced, program and school availability and parenting challenges home schooling and coordinating homecare. Most notable was the delay or lack of access to school and community programs such as day habilitation programs, job coaching and training supports, and the lack of a structured day for their children. Further, parents reported negative outcomes with remote learning during the pandemic. Many parents reported that their child could not self-direct or stay focused to complete assignments independently. Parents reported that for those children who were still in high school, there were no special accommodations that were common during in-school learning such as aides during online learning to help with organization and technology.

Theme 2: Community and School Pre-Preparation for Transitioning

In eight of the 10 interviews parents reported that there was minimal transition planning in schools and when it did occur, it was closer to graduation. Participant 7 described the experience,

> Yeah, that we started thinking okay you know we need to you know once he's 21 and he's not going to be in high school anymore. What's our plan going to be what

> are we going to do…. but just figuring out, you know what he's going to do for work, you know, even if it's just a volunteer basis. But yeah, I guess it did start around that age, it's kind of hard to remember to be honest but must have been about 17 that we started thinking about that stuff.

Participant 1 was recognizing the differences they experienced based on the severity of ASD, "It's all one size fits all. If you're not that disabled, you get less services…Teachers didn't follow up and only certain programs were available". Participant 5 added, "All IEPs were the same, not individual….no communication with parents. Only college bound got services." Further, Participant 1 indicated that, "It is all one size fits all. If you're not that disabled, you get less services." They continued by recognizing the lack of options offered, "If they had had better options, workwise, maybe some secretarial type of work filing, you know more useful skills instead of just janitorial work, right, more real world application for somebody with my daughter's skill level."

Lack of individualized planning and services was a familiar sub

theme throughout all interviews. Participant 3 reported that, "Never had any individual transition planning. They are not looking at what she can do. Nothing is individual." This was repeated in participant 6 interview, "All IEPs were the same, not individual….no communication with parents. Only college bound got services... they only offer one size fits all. Schools do not prepare kids". Yet, Participant 9, who had a child who was on the higher spectrum of autism reported, "She was too advanced for what was offered at school. They only focus on kids with greater needs." Considering these results, it appears that services that were offered were not individualized to meet their child’s needs and planning for transitioning was not a priority for the school systems that the parents and children were involved.

Some parents described inclusion or mainstreaming experiences such as Participant 8, “Life skills program was great. But high school was horrible because mainstreaming did not work. She could not keep up. Tutors were not prepared.” Participant 10 noted that there were children who were not able to benefit from the *No Child Left Behind* initiative in schools, “Access of services is only available based on autism level. No child left behind is wrong. Some get left behind.” She continued to say,

> You know, I was always, I was at every single IEP meeting for the last 13 years, and I would if I had to, I would threaten an attorney, you know, I did not let back. And I think, unfortunately, because the school systems are so back funding wise, that you know the No Child Left Behind thing is kind of wrong because there are children left behind, especially if you do not have a parent advocating for them. And, you know if I was not there, she wouldn't have gotten what she has.

This was repeated by Participant 4 interview, “she did not do well in inclusion classes…classes were too overwhelming.”

Participant 5 focused on her experience trying to get services and not knowing what was available.

> How did we never get him enrolled in any of this? So, he didn't get enrolled in any of that stuff until right when he was graduating, and he didn't officially get into the program, you know, get his caseworker and all that, right, until this December, so he just got into the system for all that stuff.

Some parents, like Participant 3, reported that the school had only one plan and her daughter had to fit into an employment model. She stated,

> They want her to fit into something else like we're gonna put her in employment, you know, only options available but they're not looking at what she can do the things she likes to do. Not individualized you know, maybe they should consider her needs.

Based on the data, it appears that transition planning, whether community or school, was lacking for this group of parents. The theme of “one size fits all” was commonly shared between multiple participants. Further, participants reported that there was no transition planning or planning that did not occur until the young adult was close to graduation. In addition, mainstreaming and inclusion programs were not effective for most of the participants interviewed. Finally, bullying in schools and in the community was reported in four of the interviews.

Theme 3: Parenting Experience and ASD During Transitioning

Theme 3 was broken down into many different areas such as independence struggles, vulnerability in the community, and overlapped with other themes regarding being on auto pilot, parenting aide, and social supports. Half of the participants interviewed described their fear of what would happen when their child became independent of them. Participant 8 noted that, “We have to make sure everything is set up…we are trying to prepare her to be able to go on without us… she’s vulnerable…she needs assisted living. She is mature but not enough though. We have to leave lists everywhere.” Participant 9 described the fear of preparing their child to drive, which had come up in interviews multiple times for 4 participants, “She continues to be dependent on us for basic stuff. We are nervous about driving. She is vulnerable and she can be naïve. In addition, Participant 10 reported social vulnerability and repeated the concerns with driving. “We support her being in social situations. She goes to camp and is around other kids. We want her to get her license, but we do not push. She is vulnerable. Participant 5 continued to describe the challenges and added that financial vulnerability was a major concern to reach independence. “He doesn’t know how to financially support himself. We do money spending training. He really wants to learn how to drive but we are concerned.”

A few parents discussed supports that were available to them in the community. Participant 7 found that other parents provided a great relief through the caregiving experience,

> I guess, I definitely met some great parents through different programs like Special Olympics and through the schools. You know that have been a good support you know it's always nice to have someone to talk to who's going through the exact same thing, So yeah, I guess through school and through, you know, different activities that he did you know I've met some really great people along the way. And thank God for the respite, that he had I mean it was always great to be able to get a break.

Participant 2 commented on the effects of parenting a child with ASD and the lack of social supports. Participant 2, “20, years later and you realize, you don't really have any friends anymore because friendships take time and effort and energy, and all the things that you didn't have time for. So, I mean, most of the friends I have now are a small circle. In addition, participant 9 added, “We used to go out. But it’s been a negative impact on social situations.” Parents appeared to find supports informally in the community and during activities for their child.

Both Participant 6 and 1 talked about the challenges as being in auto pilot to meet and coordinate all their child’s need during adult transitioning and preparation. Many parents appeared to plan the best they could but ran into roadblocks as participant 1 described,

> It was just wonderful. High School. You know, but, once we got to college, I am like wow, how much did her aides and teachers really do for you right? The first semester was rough she tried to take math. And of course, her testing she had to take the pre rec, and it was all virtual, and I kept checking in on her. How are you doing how are things going well, yes mom, good. Do you need my help? No, I got it mom and her support staff called me and said, I could cry I just looked at her notes, she has no idea what she's doing, and she's gonna fail. So, my daughter and I talked, and we said, Okay, let's just drop it, and it was hard to in the fall because programs closed down and then she was home full time, you know, it was just a perfect storm, I think.

Participant 7 expanded her need to coordinate services by developing her own concept of residential placement to meet her child’s need during the transition.

> Maybe an apartment setting with three or four other guys with a similar diagnosis with staff to help with you know meal prep and bills and all that, right, that plan

> has changed drastically now that we're living in the South, there's, there aren't anywhere near the amount of services. So, I'm actually probably going to buy a big apartment, and I'm hoping to start something there myself. Where Henry can live with people, and I don't know. I don't know I'm investigating starting something on my own because there's just not enough there, and there's the need is great.

Finally, 2 participants, 7 and 2, offered positive experiences raising young adults with ASD. Participant 7 noted that having a child with special needs provides a deeper sense of empathy within the family unit. “When you have a family member with special needs, it's just it's just so different, I mean, and they help build empathy and what it brings out when you as a, as a person, it's beautiful thing. Yeah, it's pretty special.” In addition, participant 1 noted,

> Coming to appreciate all of the beauty that there is in being a parent of a child with special needs and the blessing. I really have come to think of it as a blessing that I've been able to see a different part of life than I would have been able to see, and her special needs, and I honestly truly believe it has made me a better person, It's made me a better man, a better husband, while I was married, certainly a better father than I ever would have been if she had just been normal typical.

> Although most participants described a negative effect on parenting, some of the parents did not see the special needs of their child as having a negative effect.

Participants described a positive effect on the family unit, producing shared empathy and compassion.

Theme 4: ASD Characteristics Affecting Transitioning

Characteristics of ASD interfering with successful adult integration was identified in all the 10 interviews. Participant 10 spoke about how often age may not be associated with maturity in the transition process. “She doesn’t get invited to parties. She has a hard time expressing herself. She has social anxieties and she is a little awkward. Noise triggers her. Distractions. Autism doesn’t make them adults at 18. Social anxieties and awkwardness associated with ASD was noted in many interviews. Participant 3 described anxieties due to feeling awkward and standing out in groups. “She can’t organize, can’t remember things. Kids didn’t know how to deal with her. She has a hard time with time elapse. Huge anxiety problem. Doesn’t know anything about strangers. Huge anxiety problem. This themed continued with a focus for some participants on the disconnection to social interaction. Participant 6 noted, “She can’t communicate easily. She’s disconnected. “Also, participant 5 added that, ‘He doesn’t get sarcasm. Groups exclude him.”

Participant 1 talked about the lack of skill their child had navigating environments and only wanting to focus on what they are comfortable. They said, “She needs help staying on topic. She has no insight. She only wants to focus on certain things like art. She is good at art. She cannot navigate new environments.” Participant 8 discussed the lack of social development and restrictive thinking. “She doesn’t make a lot of friends. She obsesses when she gets something in her head. She has a hard time with transitions. She needs time to settle in a new situation. She needs repetition. She doesn’t do well with people”.

In addition, participant 7 noted how others in the community lacked compassion toward children with ASD, expecting as the child gets older, they will learn basic skills,

> I feel like a broken record, like how many more times am I going to have to show this get out of brush his teeth. Right. You know and so it was a little bit of the same thing with that you know just you I just wished that they showed a little bit more compassion and I mean it's not like they're bad people by any stretch, they just didn't really understand it, but they were okay, but just not, you know, you certainly did certainly didn't give you like warm fuzzies when you walked out.

Participant 9 shared his worry that his daughter may not be able to achieve independence at the same pace as a typically developing adult. “You know I'm not sure where her road is going to lead. Certainly it's going to, you know, I guess I don't know, I just, I suspect that she won't be on the normal timeline. And, you know, is she going to be able to do that.”

These results indicated that more severe ASD characteristics interfered with their child meeting milestones and required more intense and individualized interventions.

Theme 5: ASD Parenting and Effects on Marital Satisfaction

Many parents described their struggles maintaining a relationship while raising children with ASD. Participant 7described the negative effect on marriage,

> It would definitely put a humungous strain on the marriage. It was not good. My husband and I dealt with our son and his diagnosis and him as a person really differently. There was a lot of denial as far as my husband was concerned, I hope I don't sound like I'm talking negatively about him, but it was a struggle. Our son

> got away with a lot with my husband and I knew it was not going to have a good outcome. And yeah, it was a huge struggle, I would say. I mean, I'm not gonna say ended the marriage, there was a lot of other stuff that went into it. Yeah. If he did not have a developmental disability. It would have been different. I mean, it's, it puts a toll on a marriage. It's, just really hard. I mean, every single day. And you know it's sometimes it's so hard to stay positive when it's like, feel like a broken record like this kid is 10 years old and I still have to tell him to look both ways every time he crosses the road like, I mean it's so hard sometimes to stay positive.

Yet, participant 10 noted that, although there were struggles in the relationship, raising a child with ASD made them stronger,

> We would blame each other and not communicate. Dealing with special needs kids takes it’s toll on marriage. We separated for a while. But now we have grown together. But it was stressful to deal with, counseling helped. So you know there's been a lot of different things that we've had to work through, you know, between financially and emotionally, but we managed to kind of see through it with counseling in working with our kids.

Participant 8 added, “Made my wife and I closer. Every marriage has stress. This is what we are dealt with.

Participant 2 remarked on the lack of supports and breaks within the relationship,

> It was very stressful. Took a toll on our marriage. There was a huge impact. We needed to communicate better. We needed respite and as a result we both ended up taking care of her, and neither one of us got a break and I say the real sad

> commentary is that we dated for five years we were married for 23 years, so we were together for just over 28 years, and that the only time, either one of us really got a break after she was born was after we got divorced, and then we went to every other week.

He went on to describe the epiphany he had, knowing his ex-wife had been the primary care giver for their daughter. "I said to my ex-wife, I said, you've been doing this by yourself. All this time, And I'm sorry that I wasn't a good husband. And she started crying."

These results showed that parenting a child with ASD and maintaining spousal relationships were challenging, resulting in divorce from most parents. When parents did stay together, they describe growth in the relationship, maturity, and increased compassion toward each other and their child.

Theme 6: Post-Transition Outcomes and Recommendations

> Outcomes and recommendations were reported in all 10 interviews. Participant 7, "He did really well when he got out of school, he, he just he, he struggled with you know the, you know, five days a week in school. He just, it was a lot for him he so he did better once he graduated, you know, we obviously started to move to a day job… I don't know. I think he did a lot better once he once he aged out of high school, simply because it wasn't for him to everyday, sit in the classroom deal.

Participant 10 described positive outcomes in employment and training programs,

> I mean, you know, we're taking it one step at a time, she's got to pass the class but she has to pass exams to be certified. And then once she is certified, then she can actually work as a CNA at any nursing home… she is working on her CNA and will graduate in May. She wants to help, even in a volunteer capacity.

Regression was a frequent theme after their child transitioned. Participant 6 noted, “You only matter if you’re under 22. You feel discarded after school ends. She’s declined without services and social interaction.” Participant 9 noted the continued dependence on the family after transitioning. “She continues to be dependent; she takes 2 college courses with many supports.” This theme continued with participant 5 indicating the financial dependency that has continued after transitioning. “He doesn’t know what he wants to do. Cannot financially support himself.” He doesn’t drive so he needs me to transport.” In addition, participant 8 indicated that, “She wants to live independently but cannot support herself financially. She needs assisted living program. She needs guidance.”

Other participants views were similar. Participant 1, “She’s not quite up to snuff. She doesn’t have her high school group. She is in college but only can do well in classes she likes like art. She gets tutoring help. She is naïve and vulnerable.” Participant 3 found that, “She doesn’t have any friends. She is regressing since transitioning. She can’t do anything independently.”

Recommendations included the need for individualized programming, skill development training, early preparation for adult transitioning, providing more options for employment and secondary education, and more supports for parents to help navigate and coordinate planning for their child with ASD. Participant 1 remarked, “Definitely skill, appropriate job mentoring and some real life job placements, so they can kind of figure out what they're capable of what they like doing that were more challenging. Participant 9 noted that funding is an important factor that will improve services and individualized programs. “Oh, well certainly that would apply. Everyone has the different abilities, and to cater to the specific needs, I think is, you know, paramount with success for each person, and individual basis. Yeah, unlimited money to develop these programs.”

Other recommendations from participants included mentoring programs, individualizing school and community programs, and better knowledge and access of services. Participant 4 provided, “They need to match staff and programs to kids needs. Be more sensitive to child’s needs develop student buddy system to help stop bullying…have college courses available with individual curriculums…need for parent support group.” Participant 10 added, “we need trained teachers, quality clinicians…more funding for transition planning…organizations that bring parents together…need a specialized driving school and more social groups…need the best of the best that understand the spectrum.”

Finally, participants 8, 6, 3, 7, 5 shared similar recommendations to improve adult transitioning. Important themes of recommendations include planning earlier for transition planning and the need for specialized, individualized programs. Further, there was a need throughout many interviews that there is a huge need for peer supports during transitioning and driving schools for young adults with ASD. Lastly, Participants said that there is a need for learning for parents to access supports and be prepared for the process of adult transitioning for their child with ASD.

Table 1

Themes, Categories, Codes

Themes	Categories	Codes
Negative effects of Covid on transitioning	Covid Effects on Parents	Programs unavailable Covid stopped services Regression Decline in functioning Parenting challenges with home schooling Can't self-direct Technology problems Depression
community and school pre preparation of transitioning	Pre transition	School pre transitioning No individual planning Only one size fits all Mainstreaming was negative No access Bullying overwhelming
parenting and ASD during transitioning	Parent Experience	Increasing independence Vulnerable Dependent Wants to drive Auto pilot
ASD characteristics and challenges	ASD challenges	Social anxiety Organization issues Attention issues Communication issues Socially isolated transition problems Obsessions Lack of motivation Slow processing
ASD parenting and effects on marital satisfaction	Relationships	Blame Stress Negative impact Growth Social isolation Strain on relationship Negative impact No communication

Post transition outcomes and recommendations	Post transition	Still dependent No direction Financially dependent Regressing Dependent Declined without services Need more specialized programs Need individualized programs Need support groups Peer mentoring Need trained clinicians and teachers

Summary of Findings

This research study was intended to gain insight into the experiences of parents who have children with ASD transitioning to adulthood. A qualitative, phenomenological approach was implemented to elicit rich information to answer the research question. Based on thematic analysis applied to 10 interviews, 6 themes were identified which emerged from data: negative effects of covid on transitioning, pre-transitioning in school and community, parenting and ASD during transitioning, ASD characteristics during transitioning process, ASD parenting and effects on marital satisfaction, and Transitioning outcomes and recommendations. Overall, the participants described individual and shared experiences of all six themes. Chapter 5 presents the interpretation of the findings and limitations of the study. Implications of social change and future research recommendations are also addressed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological design study was to explore the lived experiences of parents with children with ASD who are transitioning to adulthood. A phenomenological approach was appropriately aligned with my research question because I wanted to know the essence of how parents understand the transitioning process through their lived experience of their child's journey to adulthood. The research approach included identifying the essential structures or essence of the experience to concretely describe the population's world view (Hopkins, et al., 2017). Researchers have found that parents of children with ASD transitioning to adulthood continue to support and coordinate all areas of their child's life well into adulthood (Spiers, 2015; Paradiz et al., 2017). The gap in the literature stems from the lack of qualitative research exploring the lived experience of adult transitioning from the parent viewpoint (Sosnowy et al., 2018). The information from the study provided the full spectrum of the phenomenon regarding parent's view of changes in accessibility of services before and after transitioning to adulthood, how they cope with changes for themselves and their child with ASD, and what parents identified as necessary programming and barriers to their child's success as an adult.

The 10 participants of the study were parents of children with ASD at various levels of adult transitioning. A qualitative phenomenological design was used to produce deep, rich information that were thematically analyzed. In this chapter, I provide interpretation of data and findings that were presented in Chapter 4. Further, limitations, social implications, and future recommendations were addressed.

Interpretation of Findings

The significance findings of this study are provided in relation to the research question and previous research reviewed in Chapter 2. The findings of this study confirmed the ongoing need for supports, access, and individualized services for parents transitioning their child with ASD to adulthood. SI theory informed what parents define as meaningful supports, resources, and programs by identifying what was significant and necessary for their child's success as an adult. In this light, the gaps in service provision interfering with successful transitioning and communication breakdowns within relationships were apparent and extended to the school and community level. These results are consistent with the research on the lack of comprehensive, individualized programs for pre- and post transitioning programs for young adults with ASD. Research in adult transitioning with ASD show the need for supports in employment, daily life needs, and independent living skills, but there is continued gaps in service provision, understanding of individual needs, and resources and supports needed to meet goals associated with independence in adulthood (Kuo et al., 2018; Nicolas et al., 2018; Taylor et al., 2015). As the participants described their lived experiences, six themes emerged from the data: negative effects of covid on transitioning, pre transitioning in school and community, parenting and ASD during transitioning, ASD characteristics during transitioning process, ASD parenting and effects on marital satisfaction, and transitioning outcomes and recommendations.

Based on the first theme of the negative effects of COVID on adult transitioning, it is important to understand that all the 10 participants and their families experienced some level of disruption through the COVID virus pandemic. Even though this was a new experience in relation to ASD adult transitioning, there were many shared situations that the group expressed in their interviews. First, all 10 participants indicated that either school, community programs, employment, or college classes were interrupted or discontinued. These responses mimicked Spain et al. (2021) who found that people with autism are at risk for not being able to cope with the changes associated with the pandemic such as isolation or disruption in routine and expectations. Because many of the children of the participants would not do anything independently without encouragement during the pandemic, parents were left to provide home schooling without the necessary supports that were normally provided by the schools. Participant 8 described the difficulties once school stopped, “She is not doing well without class, everything just shut down and she no longer has an aide. There is no structure.” Because programs and services ended so abruptly, many of the parents described that their child had regressed or had become depressed and withdrawn. Social engagement that was once a daily experience, was no longer available for their children. Participant 6 noted, “Everything just dropped off, she’s declined, and she seems depressed.” Lugo-Marin et al. (2021) described how excessive environmental changes such as those caused from COVID may contribute to anxiety and depression for people with ASD. In addition, some participants who still had children in high school noted the struggles in technology that appears to be a common response to sudden home schooling due to the pandemic. Letzel et al. (2020) found that there were both positive and negative effects of home schooling, with an inequality of technical supports for certain groups and race.

The second theme of pre transitioning preparation in school and community expanded to include participant experiences with school, which were both negative and positive. Participants spoke about the lack of teacher follow up on issues with their child, the “one size fits all” ASD programs that were available, and the lack of individualized programming. Participant 10 explained how the No Child Left Behind movement caused their child to fall behind because of mainstreaming and high expectations for academic success. “Access of services is only available based on autism level. No child left behind is wrong. Some get left behind.” There are current researchers who focused on how the “Race to the Top”, which is a nation-wide educational initiative providing federal funds to school districts that increase academic performance and improve core standards, may negatively affect specialized and individualized programming that is at the heart of inclusion (Deas, 2018). Further, Larcombe et al. (2019) identified many factors affecting successful mainstreaming that include class size, individual social/behavioral characteristics, availability of teacher assistants, and peer understanding and exposure to others with ASD.

In addition, participants went on to explain their experiences trying to find school and community programs to help prepare their child for adulthood. Participant 1, 3, 4, 5, 6, and 9 noted they found that there was a challenge accessing individualized options, transition planning, and options to inclusion or specialized programs. Based on the results of the literature review on transition planning, there is a need to provide early and ongoing planning for students with ASD that focuses on strength-based approaches (Hume et al., 2017). Participant 3 explained this frustration they experienced, “We never had any individual transition planning. They’re not looking at what she can do. Nothing is individual. They only offered certain things and you had to fit in to that program.

Further, parents said that services that were offered were specific for those with a certain level of ASD and that those who were higher and lower functioning failed to receive services depending on the school and the community offerings. Participants 5 and 9 had both indicated that their child was not receiving appropriate services, despite both children being on the higher spectrum of ASD. Participant 5 described it as, “All IEPs were the same, not individual…no communication with parents. Only college bound got services. In addition, Participant 9 noted that, “She was too advanced for what was offered at school. They only focus on kids with greater needs.” Research indicated a similar phenomenon regarding transition planning in that it occurs at a lower rate in secondary school for those with ASD compared with other disabilities, students with ASD do not appear to know what opportunities are available, and they report that they are not a part of transitioning conversations (Chandroo et al., 2018, 2020; Hendrickson et al., 2017).

The third theme that was revealed from the data describes parenting and ASD during adult transitioning. All the participants wanted their child to achieve independence as an adult. Despite this belief, all reported that their child continued to be dependent on parents for most of their needs. Parents report that they are still providing supports after their child has “aged out” of the programs in their communities and are no longer eligible, but their roles and coordination processes continues as well as their advocacy efforts to access services for their adult children (Milan & Nicolas, 2017; Platos et al., 2019). Many parents reported that their children are not mature enough to live independently, citing vulnerabilities with using transportation, not having the skill set to drive safely, lack of communication and social skills, and not being able to secure financial independence. Research confirms these outcomes indicating limited social integration, poor outcomes with employment opportunities, and a lack of understanding of how to reach positive mental health, occupational, and social outcomes (Anderson et al., 2017; Howlin & Magiati, 2017; Wittenburg et al., 2019).

Parents in the study noted the need to plan for their child's future and the stress and hard work this produced. Three participants described their struggles coordinating all that was needed as being on autopilot, trying to maintain the family unit. It appears from the research that caregiver strain may differ across the lifespan of the child with ASD and is dependent on if there is accessibility of services, personal family coping styles, and internal and external triggers for strain (Shivers et al., 2017). Two of the participants noted that they experienced affiliated stigma, or that the parents felt stigmatized due to their child's ASD. Participant 9 explained that other parents no longer invited them over due to the need to bring their child with them in social get togethers. Zhou et al (2018) found that care givers who experience affiliated stigma have higher depression levels, feel shame, and may be a predictor of psychological problems.

Yet, there were two participants who stated that raising a child with special needs was an overall positive experience. They noted that they developed more empathy towards others, brought a great sense of accomplishment, and made them into better parents and human beings. Participant 2 stated,

> I’ve come to appreciate all of the beauty that there is in being a parent of a child with special needs and the blessing. I really have come to think of it as a blessing. I've been able to see a different part of life than I wouldn’t have seen if she didn’t special needs, and I honestly truly believe it has made me a better person.

Researchers identified that parents that are more educated regarding ASD and have higher self-efficacy with strategies to cope with issues associated with ASD have greater satisfaction in the caregiving process (Salas et al., 2017).

The fourth theme identified was ASD characteristics during adult transitioning. All 10 participants found that their child’s ASD interfered with transitioning at some level. Participants described ASD characteristics such as social awkwardness, sensory sensitivities, restrictive thinking, social anxieties, learning difficulties, organization and transitioning issues, attention deficits, time management problems and lack of social cues, created problems transitioning causing a disconnection with engaging, group exclusion, and social stigmatization. Despite these struggles, the parents interviewed focused on their child’s strengths to develop realistic plans through transitioning and acceptance of their uniqueness. Thompson et al. (2017) found that parents of children with ASD do not want to marginalize their children based on their deficits and approach adult transitioning by leveraging their child’s strengths to reach their goals. In addition, families that identify with a strength-based approach to adult transitioning versus a deficit that cannot be changed, support an individualized and specialized approach to assimilating to adult living (Thompson et al., 2017).

Five of the participants described their child as having anxiety or depression that interfered with their child socially engaging and had caused self-isolation during the time of adult transitioning. Researchers found that social isolation and lack of opportunities for adults with ASD often lead to mental health issues that may include depression, anxiety, social anxiety disorder (Keller et al., 2020). Three of the participants characterized their child as higher functioning and all three had children going to college at some level. Based on these results, children with ASD who a co-occurring intellectual disability do not have a higher prevalence for anxiety, depression, and chronic sleep issues (Baker-Ericzen et al., 2015; Ung et al., 2015).

The fifth theme identified was effects of ASD transitioning on relationships. Marital satisfaction was a common subtheme, with the majority stating that raising a child with ASD caused a negative impact on their relationship. Eight out of 10 parents reported that their marriages ended in part due to the strain of caregiving and extra burdens of supporting ASD issues. Hartley et al. (2017) found that negative effects were prevalent and associated with less couple time together, stress of responding to challenging behavioral needs, less partner closeness and interactions, and fewer positive interactions.

There were two participants who agreed that their marriage was strained due to the specialized needs of their child, yet they found ways to address their stress, improve communication, and identified that their relationships were currently stronger than they had been when their child was younger. Hartley et al. (2017) found a positive effect from the negativity of lack of engagement and cooperation during parenting and the ensuing conflict that occurs may cause couples with children with ASD to have more sensitivity to one another because they have a level of empathy from their shared experience.

Finally, the sixth theme was ASD and transitioning outcomes and recommendations. All participants had young adults with ASD transitioning to adulthood at various levels. Parents reported a range of outcomes based on the context where it was occurring. While most parents reported decline or regression for their child after high school, others found that their child was flourishing. Negative outcomes were associated with different factors such as lack of maturity to navigate a new environment and loss of the high school social group and routine. These results are like current research with young adults with ASD transitioning to adulthood continuing to have poor outcomes in securing competitive employment, developing, and maintaining peer relationships, and accessing post-secondary education (Baker-Ericzen et al., 2018; Chen et al., 2018; Shattuck et al., 2020).

Lack of skills communicating and interacting with others was also a boundary that limited opportunities for employment or college. Parents described feeling discarded and isolated from programs once their child left high school and noted frustration trying to access specialized, individual employment, residential, or educational services. McGee Hassrick et al. (2020) described a “service-cliff” when disruption occurs from losing eligibility and access to programs and services that were previously provided at the secondary level. Parents who had children in this older age group reported continued dependence for all their child's needs.

Finally, most of the parents made recommendations to improve programs and services at various stages of adult transitioning. Early planning and preparation during high school was a theme throughout the interviews. Parents wanted to have more options with individualized programs, tutoring services, pre-employment experiences, real world experiences practicing social skills and emotional regulation, and employment skills. Parents noted the need for more funding for transitioning services and highly trained teachers and professionals that understand the spectrum of autism. Lastly, parents expressed a need for more supports educating them on transitioning, improving access to information on transitioning, and providing more parent and organization support to improve transitioning outcomes.

Limitations of Study

There are multiple challenges that were addressed while conducting this study. First, in qualitative research, the researcher is the primary data collection instrument and has the potential to influence the process and results of a study (Patton, 2015). Transparency throughout the research process must be obvious to address subjective views that could affect the trustworthiness of the results. These biases must be addressed during all parts of the writing process. To address the researcher positionality as the primary instrument of the study, a 3-1 phenomenological framework was employed. Documentation was used through journaling and memos prior to the research and throughout the recruiting, interviewing, data analysis, and result stages. This documentation strengthened the trustworthiness of the results by identifying accuracies and inconsistencies between participants based on the interpretation of the researcher experience.

Next, the COVID-19 pandemic has impacted and affected how I accessed participants for a phenomenological study. Although face-to-face interviews are considered the gold standard to access the richest and most authentic data, this was not possible due to the pandemic. Therefore, peer-to-peer phone interviews were used. Finally, there was a back-up plan for issues that occurred recruiting because the nonprofit agency that advocates for children and family issues addressing ASD was unwilling to help recruit through their email system. Snowball sampling was applied to known parents who have children with ASD transitioning to adulthood.

Recommendations

In response to the growing numbers of people with ASD entering college and the workforce, there is a push to meet the needs of these individuals through specialized approaches (Chan et al., 2018). Young adults with ASD transitioning to adulthood continue to have poor outcomes in securing competitive employment, developing, and maintaining peer relationships, and accessing post-secondary education (Baker-Ericzen et al., 2018; Chen et al., 2018; Shattuck et al., 2020). All the participants described struggles with their children attempting to navigate adult transitioning. Whether their child was staying in high school until 21 or attempting employment or college, all parents reported the need for more individualized programming and employment opportunities to match their child’s needs and skills to improve transitioning outcomes. Individuals who have varied choices other than employment in a facility setting or a sheltered workshop have better employment outcomes (Bush & Tesse, 2017). Parents noted that there is little transition planning in school and the programs and educational opportunities that are offered are one size fits all. Transition planning occurs at a lower rate in secondary school for those with ASD compared with other disabilities, students with ASD do not appear to know what opportunities are available, and they report that they are not a part of transitioning conversations (Chandroo et al., 2018; Chandroo et al., 2020; Hendrickson et al., 2017).

After high school, parents noted concerns in college and employment environments. Parents identified the lack of inclusion and individualized curriculum on college campuses. Many students with ASD may have impairments in executive functioning associated with problem solving and may struggle with concentration in class, focusing on independent instruction, negotiating a large campus with multiple class assignments, and as a result, may experience depression, anxiety, and adjustment issues (Dallas et al., 2015). Parents reported that when employment was successful, their child had job coaching support on site and were working in a job that was a good match for their child. Parents advocated for individualized employment opportunities that reflected the skill set of their child.

In addition, participants identified a lack of opportunities for their child to socialize and improve social skills, peer engagement, and interaction in a typical setting. Parents recommended peer mentoring groups, social groups in high school and college, and a focus on inclusion at different levels. Lack of social engagement skills such as sustained eye contact, emotional reciprocity, lack of communication skills, and misinterpretation of social cues and behavior interfere with successful engagement (Strunz et al., 2017). Marginalization was reported by some parents, describing a stigma that their child experienced throughout their school experience. Broady et al. (2017) found that stigmatization continues to be prevalent in schools and communities, felt by both parents and their children with ASD. Attitudes toward ASD in the school setting by TD peers does improve as children get older but there continues to be a negative attitude toward students with ASD well into later high school years (Aube et al., 2020).

Recommendations for future studies include a more in-depth investigation of areas that were briefly reported. Bullying, marginalization, family unit experiences, and extended family supports are areas to consider. Further, a mixed method approach would provide for an expansion of information on factors associated with poor ASD transition outcomes. Included would be an examination of transition programs and the factors associated with supports for families, schools, and community programs. Finally, quantitative data regarding demographics, financial level, number of family members, school budgeting for transitioning, parent education background, and parent lifestyle would provide predictors for successful transitioning to adulthood. Because ASD characteristics and severity changes over time for a person with ASD, a longitudinal study would provide important information based on different times of growth toward independence.

Implications of Social Change

This research filled the gap in understanding the experiences of parents with children transitioning to adulthood who are diagnosed with autism spectrum disorder (ASD). The study provided much needed insight into parents lived experiences while their child with ASD transitions from adulthood and focus on what it is like from the parent viewpoint (Este et al., 2019; Shattuck et al., 2020). The key players that could benefit from this research are parents of northern New York with ASD children, supports and service through nonprofit organizations such as Wildwood Programs, Center for Disability Services, Prospect Child and Family Services, Albany Warren Washington ARC, Community, Work, and Independence, Inc., and agencies advocating for families such as Autism Alliance, Office of People with Developmental Disabilities (OPWDD) and NYSACRA (New York State Association of Community and Residential agencies). Understanding the phenomenon from the parent perspective was critical because the information has the potential to affect resources, funding, programming, and life skill development currently lacking after the transition phase (First et al., 2016; Milan & Nicolas, 2017). The knowledge gained informed professional practice in the needed areas of pre-planning programs in social skill training, competitive employment training, budgeting, and life skills training, and affective advocacy, grant availability, and policy development that supports successful adult transitioning (Kuo et al., 2018; Nicolas et al., 2018; Taylor et al., 2015). Whatever the potential implications, affecting positive social change for parents of young adults with ASD is meaningful for these reasons and this study may have the potential to provide a foundation for future research in this specialized area of life transitions.

Conclusion

In this study, I explored the lived experiences of parents with ASD who are transitioning to adulthood. Parents reflected on their child’s progress at many levels of transitioning with some children still in high school and others experiencing employment or post-secondary school. Researchers who report on the topic of ASD and adult transitioning describe overall negative outcomes for young adults with ASD during adult transitioning. There is a discrepancy in rates of success for people with ASD versus their typically developing peers. Individualized approaches to transition planning, pre-employment training, social skills training, and college preparation all improve prospects to meet successful outcomes (Hendrickson et al., 2017; Shattuck et al., 2020). Yet, the participants in the study consistently reported the lack of individualized, accessible programs that support the transitioning process. Given the negative outcomes reported in this study that confirmed the existing research, it is essential to improve upon current planning and preparation services and to expand knowledge about ASD and adult transitioning through the parent lived experience.

References

Accardo, A. L., Kuder, S. J., & Woodruff, J. (2019). Accommodations and support services preferred by college students with autism spectrum disorder. *Autism*, *23*(3), 574-583. http://dx.doi.org/10.1177/1362361318760490

Adams, C., & van Manen, M. A. (2017). Teaching phenomenological research and writing. *Qualitative Health Research*, *27*(6), 780-791. http://dx.doi.org/10.1177/1049732317698960

Adler-Nissen, R. (2016). The social self in international relations: Identity, power and the symbolic interactionist roots of constructivism. *European Review of International Studies*, *3*(3), 27-39. http://dx.doi.org/10.3224/eris.v3i3.27340

Agran, M., Wojcik, A., Cain, I., Thoma, C., Achola, E., Austin, K.M., Nixon, C.A., & Tamura, R. B. (2017). Participation of students with intellectual and developmental disabilities in extracurricular activities: Does inclusion end at 3: 00?. *Education and Training in Autism and Developmental Disabilities*, *52*(1), 3-12. https://www.jstor.org/stable/26420371

Amaral, D.G., Li, D., Libero, L., Solomon, M., Van de Water, J., Mastergeorge, A., Naigles, L., Rogers, S., & Wu Nordahl, C. (2017). In pursuit of neurophenotypes: The consequences of having autism and a big brain. *Autism Research*, *10*(5), 711-722. http://dx.doi.org/10.1002/aur.1755

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders, Fifth Edition (DSM-5)*. Author.

Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics*, *141*(Supplement 4), S300-S305. http://dx.doi.org/10.1542/peds.2016-4300G

Anderson, K. A., McDonald, T. A., Edsall, D., Smith, L. E., & Taylor, J. L. (2016). Postsecondary expectations of high-school students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 16-26. http://dx.doi.org/10.1177/1088357615610107

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: a review of qualitative studies. *Pediatrics*, *141*(4), S318-S327. http://dx.doi.org/10.1542/peds.2016-4300I

Andersson, G. W., Miniscalco, C., & Gillberg, N. (2017). A 6-year follow-up of children assessed for suspected autism spectrum disorder: Parents' experiences of society's support. *Neuropsychiatric disease and treatment*, *13*, 1783. https://doi.org/10.2147/NDT.S134165

Ashbaugh, K., Koegel, R. L., & Koegel, L. K. (2017). Increasing social integration for college students with autism spectrum disorder. *Behavioral Development Bulletin*, *22*(1), 183. http://dx.doi.org/10.1037/bdb0000057

Aubé, B., Follenfant, A., Goudeau, S., & Derguy, C. (2020). Public stigma of autism spectrum disorder at school: Implicit attitudes matter. *Journal of Autism and Developmental Disorders*, 1-14. https://doi.org/10.1007/s10803-020-04635-9

Baker-Ericzén, M.J., Fitch, M.A., Kinnear, M., Jenkins, M.M., Twamley, E.W., Smith, L., Montano, G., Feder, J., Crooke, P.J., Winner, M.G., & Leon, J. (2018).

Development of the Supported Employment, Comprehensive Cognitive Enhancement, and Social Skills program for adults on the autism spectrum: Results of initial study. *Autism*, *22*(1), 6-19. https://doi.org/10.1177%2F1362361317724294

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, *20*(4), 483-495. http://dx.doi.org/10.1177/1362361315590805

Barker, K., & Galardi, T. R. (2015). Diagnostic domain defense: Autism spectrum disorder and the DSM-5. *Social Problems*, *62*(1), 120-140. http://dx.doi.org/10.1093/socpro/spu001

Barnett, J. H. (2018). Three evidence-based strategies that support social skills and play among young children with autism spectrum disorders. *Early Childhood Education Journal*, *46*(6), 665-672. http://dx.doi.org/10.1007/s10643-018-0911-0

Baum, S. H., Stevenson, R. A., & Wallace, M. T. (2015). Behavioral, perceptual, and neural alterations in sensory and multisensory function in autism spectrum disorder. *Progress in neurobiology*, *134*, 140-160. http://dx.doi.org/10.1016/j.pneurobio.2015.09.007

Bearss, K., Burrell, T. L., Stewart, L., & Scahill, L. (2015). Parent training in autism spectrum disorder: What's in a name? *Clinical child and family psychology review*, *18*(2), 170-182. http://dx.doi.org/10.1007/s10567-015-0179-5

Bearss, K., Johnson, C., Smith, T., Lecavalier, L., Swiezy, N., Aman, M., McAdam, D.B., Butter, E., Stillitano, C., Minshawi, N., & Sukhodolsky, D. G. (2015).

Effect of parent training vs parent education on behavioral problems in children with autism spectrum disorder: a randomized clinical trial. *Jama*, *313*(15), 1524-1533. http://dx.doi.org/10.1007/s10567-015-0183-9

Beggiato, A., Peyre, H., Maruani, A., Scheid, I., Rastam, M., Amsellem, F., Gillberg, C.I., Leboyer, M., Bourgeron, T., Gillberg, C. and Delorme, R., & Delorme, R. (2017). Gender differences in autism spectrum disorders: Divergence among specific core symptoms. *Autism Research*, *10*(4), 680-689. http://dx.doi.org/10.1002/aur.1715

Bell, S., Devecchi, C., Mc Guckin, C., & Shevlin, M. (2017). Making the transition to post-secondary education: opportunities and challenges experienced by students with ASD in the Republic of Ireland. *European Journal of Special Needs Education*, *32*(1), 54-70. http://dx.doi.org/10.1080/08856257.2016.1254972

Berkovits, L., Eisenhower, A., & Blacher, J. (2017). Emotion regulation in young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *47*(1), 68-79. http://dx.doi.org/10.1007/s10803-016-2922-2

Bicehouse, V., & Faieta, J. (2017). IDEA at age forty: Weathering common core standards and data driven decision making. *Contemporary Issues in Education Research (CIER)*, *10*(1), 33-44. http://dx.doi.org/10.19030/cier.v10i1.9878

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. University of California Press.

Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*, *120*(5), 395-411. http://dx.doi.org/10.1352/1944-7558-120.5.395

Bohadana, G., Morrissey, S., & Paynter, J. (2019). Self-compassion: a novel predictor of stress and quality of life in parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(10), 4039-4052. http://dx.doi.org/10.1007/s10803-019-04121-x

Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & Social Care in the Community*, *25*(1), 224-233. http://dx.doi.org/10.1111/hsc.12297

Brown, K. R., & Coomes, M. D. (2016). A spectrum of support: Current and best practices for students with autism spectrum disorder (ASD) at community colleges. *Community College Journal of Research and Practice*, *40*(6), 465-479. http://dx.doi.org/10.1080/10668926.2015.1067171

Brown, M., Whiting, J., Haque, A., & Kahumoku-Fessler, E. (2020). A summative content analysis of stress and coping among parents of children with autism. *American Journal of Family Therapy*, 1-14. https://doi.org/10.1080/01926187.2020.1791764

Burke, M., & Heller, T. (2016). Individual, parent and social–environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research*, *60*(5), 401-411. http://dx.doi.org/10.1111/jir.12271

Burrell, A., Ives, J., & Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(4), 1135-1147. http://dx.doi.org/10.1007/s10803-017-3035-2

Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual disability, autism, and down syndrome. *Research in Developmental Disabilities*, *65*, 23-34. http://dx.doi.org/10.1016/j.ridd.2017.04.004

Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness, stress and well-being in parents of children with autism spectrum disorder: a systematic review. *Journal of Child and Family Studies*, *25*(1), 1-14. http://dx.doi.org/10.1007/s10826-015-0193-8

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473-484. http://dx.doi.org/10.1007/s10803-017-3342-7

Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *46*(1), 31-41. http://dx.doi.org/10.1007/s10803-015-2535-1

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). ‘People like me don’t get support’: Autistic adults’ experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431-1441. http://dx.doi.org/10.1177/1362361318816053

Candon, M. K., Barry, C. L., Marcus, S. C., Epstein, A. J., Kennedy-Hendricks, A., Xie, M., & Mandell, D. S. (2019). Insurance mandates and out-of-pocket spending for children with autism spectrum disorder. *Pediatrics*, *143*(1). http://dx.doi.org/10.1542/peds.2018-0654

Carrington, S., Berthelsen, D., Nickerson, J., Nicholson, J. M., Walker, S., & Meldrum, K. (2016). Teachers' experiences of inclusion of children with developmental disabilities across the early years of school. *Journal of Psychologists and Counsellors in Schools*, *26*(2), 139-154. http://dx.doi.org/10.1017/jgc.2016.19

Carter, M. J., & Fuller, C. (2016). Symbols, meaning, and action: The past, present, and future of symbolic interactionism. *Current Sociology*, *64*(6), 931-961. http://dx.doi.org/10.1177/0011392116638396

Case-Smith, J., Weaver, L. L., & Fristad, M. A. (2015). A systematic review of sensory processing interventions for children with autism spectrum disorders. *Autism*, *19*(2), 133-148. http://dx.doi.org/10.1177/1362361313517762

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, *50*(10), 3638-3648. http://dx.doi.org/10.1007/s10803-019-04323-3

Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *48*, 44-52. http://dx.doi.org/10.1016/j.rasd.2018.01.001

Chan, W., Smith, L. E., Hong, J., Greenberg, J. S., Lounds Taylor, J., & Mailick, M. R.

(2018). Factors associated with sustained community employment among adults with autism and co-occurring intellectual disability. *Autism*, *22*(7), 794-803. http://dx.doi.org/10.1177/1362361317703760

Chandroo, R., Strnadova, I., & Cumming, T. M. (2018). A systematic review of the involvement of students with autism spectrum disorder in the transition planning process: Need for voice and empowerment. *Research in Developmental Disabilities*, *83*, 8-17. http://dx.doi.org/10.1016/j.ridd.2018.07.011

Chandroo, R., Strnadová, I., & Cumming, T. M. (2020). Is it really student-focused planning? Perspectives of students with autism. *Research in Developmental Disabilities*, *107*, 103783. https://doi.org/10.1016/j.ridd.2020.103783

Chatterji, P., Decker, S. L., & Markowitz, S. (2015). The Effects of Mandated Health Insurance Benefits for Autism on Out□of□Pocket Costs and Access to Treatment. *Journal of Policy Analysis and Management*, *34*(2), 328-353. http://dx.doi.org/10.1002/pam.21814

Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & Koegler, E. (2017). Exploration and comparison of adolescents with autism spectrum disorder and their caregiver's perspectives on transitioning to adult health care and adulthood. *Journal of pediatric psychology*, *42*(9), 1028-1039. http://dx.doi.org/10.1093/jpepsy/jsx075

Chen, J., Cohn, E. S., & Orsmond, G. I. (2019). Parents' future visions for their autistic transition-age youth: Hopes and expectations. *Autism*, *23*(6), 1363-1372. http://dx.doi.org/10.1177/1362361318812141

Cheuk, S., & Lashewicz, B. (2016). How are they doing? Listening as fathers of children with autism spectrum disorder compare themselves to fathers of children who are typically developing. *Autism*, *20*(3), 343-352. https://doi.org/10.1177%2F1362361315584464

Chou, Y. C., Wehmeyer, M. L., Shogren, K. A., Palmer, S. B., & Lee, J. (2017). Autism and self-determination: Factor analysis of two measures of self-determination. *Focus on Autism and Other Developmental Disabilities*, *32*(3), 163-175. http://dx.doi.org/10.1177/1088357615611391

Christensen, D.L., Braun, K.V.N., Baio, J., Bilder, D., Charles, J., Constantino, J.N., Daniels, J., Durkin, M.S., Fitzgerald, R.T., Kurzius-Spencer, M., & Lee, L.C. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, *65*(13), 1. http://dx.doi.org/10.15585/mmwr.ss6513a1

Conner, C. M., White, S. W., Beck, K. B., Golt, J., Smith, I. C., & Mazefsky, C. A. (2019). Improving emotion regulation ability in autism: The Emotional Awareness and Skills Enhancement (EASE) program. *Autism*, *23*(5), 1273-1287. http://dx.doi.org/10.1177/1362361318810709

Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities*, *47*, 451-465. http://dx.doi.org/10.1016/j.ridd.2015.09.001

Cox, B.E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., Edelstein, J., & Wolz, A. (2017). College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, *58*(1), 71-87. http://dx.doi.org/10.1353/csd.2017.0004

Crowell, J. A., Keluskar, J., & Gorecki, A. (2019). Parenting behavior and the development of children with autism spectrum disorder. *Comprehensive Psychiatry*, *90*, 21-29. http://dx.doi.org/10.1016/j.comppsych.2018.11.007

Cunliffe, A. L. (2016). Republication of "On becoming a critically reflexive practitioner". *Journal of Management Education*, *40*(6), 747-768. https://doi.org/10.1177%2F1052562916674465

Cypress, B. (2018). Qualitative research methods: A phenomenological focus. *Dimensions of Critical Care Nursing*, *37*(6), 302-309. http://dx.doi.org/10.1097/DCC.0000000000000322

Dallas, B. K., Ramisch, J. L., & McGowan, B. (2015). Students with autism spectrum disorder and the role of family in postsecondary settings: A systematic review of the literature. *Journal of Postsecondary Education and Disability*, *28*(2), 135-147. https://files.eric.ed.gov/fulltext/EJ1074657.pdf

Dardas, L. A., & Ahmad, M. M. (2015). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life?. *Research in Developmental Disabilities*, *36*, 620-629. http://dx.doi.org/10.1016/j.ridd.2014.10.047

DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2018). Transitioning together: A multi-family group psychoeducation program for adolescents with ASD and their parents. *Journal of Autism and Developmental Disorders*, *48*(1), 251-263. http://dx.doi.org/10.1007/s10803-017-3307-x

de Bruin, E. I., Blom, R., Smit, F. M., van Steensel, F. J., & Bögels, S. M. (2015). MYmind: Mindfulness training for youngsters with autism spectrum disorders and their parents. *Autism*, *19*(8), 906-914. http://dx.doi.org/10.1177/1362361314553279

De Groot, K., & Van Strien, J. W. (2017). Evidence for a broad autism phenotype. *Advances in Neurodevelopmental Disorders*, *1*(3), 129-140. http://dx.doi.org/10.1007/s41252-017-0021-9

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism*, *21*(6), 678-689. http://dx.doi.org/10.1177/1362361316671845

Deas, K. (2018). Evaluating Common Core: Are Uniform Standards a Silver Bullet for Education Reform?. *The Journal of Educational Foundations*, *31*(3/4), 47-62.

Demer, L. L. (2018). The autism spectrum: human rights perspectives. *Pediatrics*, *141*(Supplement 4), S369-S372. http://dx.doi.org/10.1542/peds.2016-4300O

Denzin, N. K. (2016). Symbolic interactionism. *The International Encyclopedia of Communication Theory and Philosophy*, 1-12. http://dx.doi.org/10.1002/9781118766804.wbiect143

DePape, A. M., & Lindsay, S. (2015). Parents’ experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, *25*(4), 569-583. http://dx.doi.org/10.1177/1049732314552455

Desiningrum, D. R. (2018). Grandparents’ roles and psychological well-being in the elderly: a correlational study in families with an autistic child. *Enfermeria clinica*, *28*, 304-309. http://dx.doi.org/10.1016/S1130-8621(18)30175-X

Dewinter, J., De Graaf, H., & Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(9), 2927-2934. http://dx.doi.org/10.1007/s10803-017-3199-9

Doernberg, E., & Hollander, E. (2016). Neurodevelopmental Disorders (ASD and ADHD): DSM-5, ICD-10, and ICD-11. *CNS Spectrums*, *21*(4), 295-299. http://dx.doi.org/10.1017/S1092852916000262

Douglas, M. D., Benevides, T. W., & Carretta, H. (2017). Analyzing state autism private insurance mandates for allied health services: A pilot study. *OTJR: Occupation, Participation and Health*, *37*(4), 218-226. http://dx.doi.org/10.1177/1539449217730355

DuBois, D., Lymer, E., Gibson, B. E., Desarkar, P., & Nalder, E. (2017). Assessing sensory processing dysfunction in adults and adolescents with autism spectrum disorder: a scoping review. *Brain Sciences*, *7*(8), 108. http://dx.doi.org/10.3390/brainsci7080108

Durig, A. (1996). *Autism and the Crisis of Meaning*. SUNY Press.

Eapen, V., Grove, R., Aylward, E., Joosten, A. V., Miller, S. I., Van Der Watt, G., Fordyce, K., Dissanayake, C., Maya, J., Tucker, M., & DeBlasio, A. (2017). Transition from early intervention program to primary school in children with autism spectrum disorder. *World Journal of Clinical Pediatrics*, *6*(4), 169. http://dx.doi.org/10.5409/wjcp.v6.i4.169

Eckerd, M. (2019). Disclosure of ASD Diagnosis to Children and Adolescents. *Journal of Health Service Psychology*, *45*(1), 17-22. http://dx.doi.org/10.5409/wjcp.v6.i4.169

Eilenberg, J. S., Paff, M., Harrison, A. J., & Long, K. A. (2019). Disparities based on race, ethnicity, and socioeconomic status over the transition to adulthood among adolescents and young adults on the autism spectrum: a systematic review. *Current Psychiatry Reports*, *21*(5), 32. http://dx.doi.org/10.1007/s11920-019-1016-1

Eroglu, M., & Kilic, B.G. (2020). Peer bullying among children with autism spectrum disorderin formal educational settings: data from Turkey. *Research in Autism Spectrum Disorder*, 75, 1-7. Doi-/10.1016/j.rasd.2020.101572

Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., & Dawson, G. (2015). Long-term outcomes of early intervention in 6-year-old children with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *54*(7), 580-587. https://doi.org/10.1016/j.jaac.2015.04.005

Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Pediatric Medicine*

(Hong Kong, China), *2*. http://dx.doi.org/10.1016/j.jaac.2015.04.005

Falkmer, M., Anderson, K., Joosten, A., & Falkmer, T. (2015). Parents' perspectives on inclusive schools for children with autism spectrum conditions. *International Journal of Disability, Development and Education*, *62*(1), 1-23. http://dx.doi.org/10.1080/1034912X.2014.984589

Finnegan, E., & Mazin, A. L. (2016). Strategies for increasing reading comprehension skills in students with autism spectrum disorder: A review of the literature. *Education and Treatment of Children*, *39*(2), 187-219. https://doi.org/10.1353/etc.2016.0007

First, J., Cheak-Zamora, N. C., & Teti, M. (2016). A qualitative study of stress and coping when transitioning to adulthood with autism spectrum disorder. *Journal of Family Social Work*, *19*(3), 220-236. http://dx.doi.org/10.1080/10522158.2016.1185074

Fisher, K. W., Williamson, H., & Guerra, N. (2020). Technology and Social Inclusion: Technology Training and Usage by Youth With IDD in the National Longitudinal Transition Study of 2012. *Inclusion*, *8*(1), 43-57. http://dx.doi.org/10.1352/2326-6988-8.1.43

Franchini, M., Wood de Wilde, H., Glaser, B., Gentaz, E., Eliez, S., & Schaer, M. (2016). Brief report: A preference for biological motion predicts a reduction in symptom severity 1 year later in preschoolers with autism spectrum disorders. *Frontiers in Psychiatry*, *7*, 143. http://dx.doi.org/10.3389/fpsyt.2017.00058

Franzese A., & Seigler C. (2020) Symbolic Interactionism. In: Zeigler-Hill V., Shackelford T.K. (eds) Encyclopedia of Personality and Individual Differences. Springer, Cham. https://doi.org/10.1007/978-3-319-24612-3_2125

Frost, K. M., Bailey, K. M., & Ingersoll, B. R. (2019). "I Just Want Them to See Me As… Me": Identity, Community, and Disclosure Practices Among College Students on the Autism Spectrum. *Autism in Adulthood*, *1*(4), 268-275. http://dx.doi.org/10.1089/aut.2018.0057

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism*, *22*(5), 571-584. http://dx.doi.org/10.1177/1362361316687989

García-López, C., Sarriá, E., & Pozo, P. (2016). Parental self-efficacy and positive contributions regarding autism spectrum condition: An actor–partner interdependence model. *Journal of Autism and Developmental Disorders*, *46*(7), 2385-2398. http://dx.doi.org/10.1007/s10803-016-2771-z

Geelhand, P., Bernard, P., Klein, O., Van Tiel, B., & Kissine, M. (2019). The role of gender in the perception of autism symptom severity and future behavioral development. *Molecular Autism*, *10*(1), 1-8. https://doi.org/10.1186/s13229-019-0266-4

Gibbons, M. M., Cihak, D. F., Mynatt, B., & Wilhoit, B. E. (2015). Faculty and student attitudes toward postsecondary education for students with intellectual disabilities and autism. *Journal of Postsecondary Education and Disability*, *28*(2), 149-162. https://files.eric.ed.gov/fulltext/EJ1074661.pdf

Gillespie-Lynch, K., Bublitz, D., Donachie, A., Wong, V., Brooks, P. J., & D'Onofrio, J. (2017). "For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students. *Frontiers in Psychology*, *8*, 544. http://dx.doi.org/10.3389/fpsyg.2017.00544

Giorgi, A., Giorgi, B., & Morley, J. (2017). The Descriptive Phenomenological Psychological Method. *The SAGE Handbook of Qualitative Research in Psychology*, 176. http://dx.doi.org/10.4135/9781526405555.n11

Golan, O., Shilo, H., & Omer, H. (2018). Non-violent resistance parent training for the parents of young adults with High Functioning Autism Spectrum Disorder. *Journal of Family Therapy*, *40*(1), 4-24. http://dx.doi.org/10.1111/1467-6427.12106

Gotham, K., Marvin, A.R., Taylor, J.L., Warren, Z., Anderson, C.M., Law, P.A., Law, J.K., & Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, *19*(7), 794-804. http://dx.doi.org/10.1177/1362361315583818

Green, S. A., Hernandez, L. M., Bowman, H. C., Bookheimer, S. Y., & Dapretto, M. (2018). Sensory over-responsivity and social cognition in ASD: Effects of aversive sensory stimuli and attentional modulation on neural responses to social cues. *Developmental Cognitive Neuroscience*, *29*, 127-139. http://dx.doi.org/10.1016/j.dcn.2017.02.005

Griffin, M. M., Mello, M. P., Glover, C. A., Carter, E. W., & Hodapp, R. M. (2016). Supporting students with intellectual and developmental disabilities in postsecondary education: The motivations and experiences of peer mentors. *Inclusion*, *4*(2), 75-88. http://dx.doi.org/10.1352/2326-6988-4.2.75

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*,18(1), 59-82. https://doi.org/10.1177%2F1525822X05279903

Guo, X., Chen, H., Long, Z., Duan, X., Zhang, Y., & Chen, H. (2017). Atypical developmental trajectory of local spontaneous brain activity in autism spectrum disorder. *Scientific Reports*, *7*(1), 1-10. http://dx.doi.org/10.1038/srep39822

Hadi, M. A., & Closs, S. J. (2016). Ensuring rigour and trustworthiness of qualitative research in clinical pharmacy. *International Journal of Clinical Pharmacy*, *38*(3), 641-646. http://dx.doi.org/10.1007/s11096-015-0237-6

Hall, D. M., Feldpausch-Parker, A., Peterson, T. R., Stephens, J. C., & Wilson, E. J. (2017). Social-ecological system resonance: a theoretical framework for brokering sustainable solutions. *Sustainability Science*, *12*(3), 381-392. http://dx.doi.org/10.1007/s11625-017-0424-6

Halladay, A.K., Bishop, S., Constantino, J.N., Daniels, A.M., Koenig, K., Palmer, K., Messinger, D., Pelphrey, K., Sanders, S.J., Singer, A.T., & Taylor, J. L. (2015). Sex and gender differences in autism spectrum disorder: summarizing evidence gaps and identifying emerging areas of priority. *Molecular autism*, *6*(1), 1-5. http://dx.doi.org/10.1186/s13229-015-0019-y

Hamilton, K., Hoogenhout, M., & Malcolm-Smith, S. (2016). Neurocognitive considerations when assessing theory of mind in autism spectrum disorder. *Journal of Child & Adolescent Mental Health*, *28*(3), 233-241. http://dx.doi.org/10.2989/17280583.2016.1268141

Harmuth, E., Silletta, E., Bailey, A., Adams, T., Beck, C., & Barbic, S. P. (2018). Barriers and facilitators to employment for adults with autism: A scoping review. *Annals of International Occupational Therapy*, *1*(1), 31-40. http://dx.doi.org/10.3928/24761222-20180212-01

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(6), 1636-1648. http://dx.doi.org/10.1007/s10803-014-2318-0

Hartley, S. L., DaWalt, L. S., & Schultz, H. M. (2017). Daily couple experiences and parent affect in families of children with versus without autism. *Journal of Autism and Developmental Disorders*, *47*(6), 1645-1658. http://dx.doi.org/10.1007/s10803-017-3088-2

Hartley, S. L., Papp, L. M., & Bolt, D. (2018). Spillover of marital interactions and parenting stress in families of children with autism spectrum disorder. *Journal of Clinical Child & Adolescent Psychology*, *47*(sup1), S88-S99. http://dx.doi.org/10.1080/15374416.2016.1152552

Hartley, S. L., Papp, L. M., Blumenstock, S. M., Floyd, F., & Goetz, G. L. (2016). The effect of daily challenges in children with autism on parents' couple problem-solving interactions. *Journal of Family Psychology*, *30*(6), 732. http://dx.doi.org/10.1037/fam0000219

Hartley, S. L., Papp, L. M., Mihaila, I., Bussanich, P. M., Goetz, G., & Hickey, E. J. (2017). Couple conflict in parents of children with versus without autism: Self-reported and observed findings. *Journal of Child and Family Studies*, *26*(8), 2152-2165. http://dx.doi.org/10.1007/s10826-017-0737-1

Hedley, D., Uljarević, M., Cameron, L., Halder, S., Richdale, A., & Dissanayake, C. (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. *Autism*, *21*(8), 929-941. http://dx.doi.org/10.1177/1362361316661855

Hendrickson, J. M., Woods-Groves, S., Rodgers, D. B., & Datchuk, S. (2017). Perceptions of students with autism and their parents: The college experience. *Education and Treatment of Children*, *40*(4), 571-596. http://dx.doi.org/10.1353/etc.2017.0025

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Brief report: What happens when i can no longer support my autistic relative? Worries about the future for family members of autistic adults. *Journal of Autism and Developmental Disorders*, *47*(11), 3659-3668. http://dx.doi.org/10.1007/s10803-017-3254-6

Hillman, J., Marvin, A. R., & Anderson, C. M. (2016). The experience, contributions, and resilience of grandparents of children with autism spectrum disorder. *Journal of Intergenerational Relationships*, *14*(2), 76-92. http://dx.doi.org/10.1080/15350770.2016.1160727

Holmes, L. G., Kirby, A. V., Strassberg, D. S., & Himle, M. B. (2018). Parent expectations and preparatory activities as adolescents with ASD transition to adulthood. *Journal of Autism and Developmental Disorders*, *48*(9), 2925-2937. http://dx.doi.org/10.1007/s10803-018-3545-6

Holtz, K. D., Owings, N. M., & Ziegert, A. K. (2006). Life Journey through Autism: A Guide for Transition to Adulthood. *Organization for Autism Research (NJ1)*. https://files.eric.ed.gov/fulltext/ED508625.pdf

Hopkins, R. M., Regehr, G., & Pratt, D. D. (2017). A framework for negotiating positionality in phenomenological research. *Medical Teacher*, *39*(1), 20-25. https://doi.org/10.1080/0142159X.2017.1245854

Howard, K. B., Katsos, N., & Gibson, J. L. (2019). The school experiences of bilingual children on the autism spectrum: An interpretative phenomenological analysis. *Research in Developmental Disabilities*, *87*, 9–20. https://doi.org/10.1016/j.ridd.2019.01.008

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, *30*(2), 69-76. http://dx.doi.org/10.1097/YCO.0000000000000308

Hsiao, Y. J., Higgins, K., Pierce, T., Whitby, P. J. S., & Tandy, R. D. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in Developmental Disabilities*, *70*, 152-162. http://dx.doi.org/10.1016/j.ridd.2017.08.013

Hu, X., Han, Z. R., Bai, L., & Gao, M. M. (2019). The mediating role of parenting stress in the relations between parental emotion regulation and parenting behaviors in

Chinese families of children with autism spectrum disorders: a dyadic analysis. *Journal of Autism and Developmental Disorders*, *49*(10), 3983-3998.http://dx.doi.org/10.1007/s10803-019-04103-z

Hull, L., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*, *24*(2), 352-363. http://dx.doi.org/10.1177/1362361319864804

Hull, L., Mandy, W., & Petrides, K. V. (2017). Behavioural and cognitive sex/gender differences in autism spectrum condition and typically developing males and females. *Autism*, *21*(6), 706-727. http://dx.doi.org/10.1177/1362361316669087

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47,* 2519-2534. DOI 10.1007/s10803-31665.5

Hume, K., Dykstra Steinbrenner, J., Sideris, J., Smith, L., Kucharczyk, S., & Szidon, K. (2018). Multi-informant assessment of transition-related skills and skill importance in adolescents with autism spectrum disorder. *Autism*, *22*(1), 40-50. http://dx.doi.org/10.1177/1362361317722029

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: a focus on under-represented families. *International Journal of Developmental Disabilities*, *65*(1), 20-30. http://dx.doi.org/10.1080/20473869.2017.1347228

Iida, N., Wada, Y., Yamashita, T., Aoyama, M., Hirai, K., & Narumoto, J. (2018). Effectiveness of parent training in improving stress-coping capability, anxiety, and depression in mothers raising children with autism spectrum disorder. *Neuropsychiatric Disease and Treatment*, *14*, 3355. http://dx.doi.org/10.2147/NDT.S188387

Ilias, K., Cornish, K., Kummar, A. S., Park, M. S. A., & Golden, K. J. (2018). Parenting stress and resilience in parents of children with Autism Spectrum Disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in Psychology*, *9*, 280. http://dx.doi.org/10.3389/fpsyg.2018.00280

Ingersoll, B., & Berger, N. I. (2015). Parent engagement with a telehealth-based parent-mediated intervention program for children with autism spectrum disorders: predictors of program use and parent outcomes. *Journal of Medical Internet Research*, *17*(10), e227. http://dx.doi.org/10.2196/jmir.4913

Jackson, S. L., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(3), 643-650. http://dx.doi.org/10.1007/s10803-017-3315-x

Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *Qualitative Report, 17*, 6. http://www.nova.edu/ssss/QR/QR17/jacob.pdf

Johnson, J. L., Adkins, D., & Chauvin, S. (2020). A review of the quality indicators of rigor in qualitative research. *American Journal of Pharmaceutical*

Education, *84*(1). https://doi.org/10.5688/ajpe7120

Johnson, R. (2015). Does the DSM-5 threaten autism service access. *Utah L. Rev.*, 803.

Jones, E. A., Fiani, T., Stewart, J. L., Sheikh, R., Neil, N., & Fienup, D. M. (2019). When one sibling has autism: adjustment and sibling relationship. *Journal of Child and Family Studies*, *28*(5), 1272-1282.http://dx.doi.org/10.1007/s10826-019-01374-z

Joshi, G., Faraone, S.V., Wozniak, J., Tarko, L., Fried, R., Galdo, M., Furtak, S.L., & Biederman, J. (2017). Symptom profile of ADHD in youth with high-functioning autism spectrum disorder: a comparative study in psychiatrically referred populations. *Journal of Attention Disorders*, *21*(10), 846-855. http://dx.doi.org/10.1177/1087054714543368

Kahana, E., Lee, J.E., Kahana, J., Goler, T., Kahana, B., Shick, S., Burk, E., & Barnes, K. (2015). Childhood autism and proactive family coping: Intergenerational perspectives. *Journal of Intergenerational Relationships*, *13*(2), 150-166.http://dx.doi.org/10.1080/15350770.2015.1026759

Karst, J. S., Van Hecke, A. V., Carson, A. M., Stevens, S., Schohl, K., & Dolan, B. (2015). Parent and Family Outcomes of PEERS: A Social Skills Intervention for Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *45*(3), 752–765. http://dx.doi.org/10.1007/s10803-014-2231-6

Keller, R., Chieregato, S., Bari, S., Castaldo, R., Rutto, F., Chiocchetti, A., & Dianzani, U. (2020). Autism in Adulthood: Clinical and Demographic Characteristics of a Cohort of Five Hundred Persons with Autism Analyzed by a Novel Multistep

Network Model. *Brain Sciences*, *10*(7), 416. http://dx.doi.org/10.3390/brainsci10070416

Keshav, N. U., Vahabzadeh, A., Abdus-Sabur, R., Huey, K., Salisbury, J. P., Liu, R., & Sahin, N. (2018). Longitudinal socio-emotional learning intervention for autism via smartglasses: Qualitative school teacher descriptions of practicality, usability, and efficacy in general and special education classroom settings. *Education Sciences*, *8*(3), 107. http://dx.doi.org/10.3390/educsci8030107

Kiami, S. R., & Goodgold, S. (2017). Support needs and coping strategies as predictors of stress level among mothers of children with autism spectrum disorder. *Autism Research and Treatment*, *2017*. http://dx.doi.org/10.1155/2017/8685950

Kiely, B., Adesman, A., Rapoport, E., & Gutman, A. (2020). Patterns and Outcomes of Diagnosis Disclosure to Youth with Autism Spectrum Disorder. *Journal of Developmental & Behavioral Pediatrics*, *41*(6), 443-451. doi: 10.1097/DBP.0000000000000802

Kim, S. H., Bal, V. H., Benrey, N., Choi, Y. B., Guthrie, W., Colombi, C., & Lord, C. (2018). Variability in autism symptom trajectories using repeated observations from 14 to 36 months of age. *Journal of the American Academy of Child & Adolescent Psychiatry*, *57*(11), 837-848. http://dx.doi.org/10.1016/j.jaac.2018.05.026

Kim, S. Y., & Bottema-Beutel, K. (2019). A meta regression analysis of quality of life correlates in adults with ASD. *Research in Autism Spectrum Disorders*, *63*, 23-33.http://dx.doi.org/10.1016/j.rasd.2018.11.004

Kirby, A. V., Bagatell, N., & Baranek, G. T. (2020). The formation of postsecondary expectations among parents of youth with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities*, *35*(2), 118-128. http://dx.doi.org/10.1177/1088357619881221

Kirby, A. V., Feldman, K. J. C., Hoffman, J. M., Diener, M. L., & Himle, M. B. (2020). Transition preparation activities and expectations for the transition to adulthood among parents of autistic youth. *Research in Autism Spectrum Disorders*, *78*, 101640. https://doi.org/10.1016/j.rasd.2020.101640

Knight, V. F., & Sartini, E. (2015). A comprehensive literature review of comprehension strategies in core content areas for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(5), 1213-1229. http://dx.doi.org/10.1007/s10803-014-2280-x

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, *24*(1), 120-124. https://doi.org/10.1080/13814788.2017.1375092

Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(3), 722-731. http://dx.doi.org/10.1007/s10803-017-3434-4

Kuhlthau, K. A., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M., & van der Weerd, E. (2016). Health care transition services for youth with autism spectrum disorders: Perspectives of caregivers. *Pediatrics*, *137*(Supplement 2), S158-S166. https://doi.org/10.1542/peds.2015-2851n

Kuo, A. A., Crapnell, T., Lau, L., Anderson, K. A., & Shattuck, P. (2018). Stakeholder perspectives on research and practice in autism and transition. *Pediatrics*, *141*(Supplement 4), S293-S299. http://dx.doi.org/10.1542/peds.2016-4300F

Kurth, J. A., Love, H., & Pirtle, J. (2020). Parent perspectives of their involvement in IEP development for children with autism. *Focus on Autism and Other Developmental Disabilities*, *35*(1), 36-46. http://dx.doi.org/10.1177/1088357619842858

Kwok, S. Y., Cheng, L., Chow, B. W., & Ling, C. C. (2015). The spillover effect of parenting on marital satisfaction among Chinese mothers. *Journal of Child and Family Studies*, *24*(3), 772-783. http://dx.doi.org/10.1007/s10826-013-9888-x

Lai, M.C., Lombardo, M.V., Chakrabarti, B., Ruigrok, A.N., Bullmore, E.T., Suckling, J., Auyeung, B., Happé, F., Szatmari, P., & Baron-Cohen, S. (2019). Neural self-representation in autistic women and association with ‘compensatory camouflaging’. *Autism*, *23*(5), 1210-1223. http://dx.doi.org/10.1177/1362361318807159

Larcombe, T. J., Joosten, A. V., Cordier, R., & Vaz, S. (2019). Preparing Children with Autism for Transition to Mainstream School and Perspectives on Supporting Positive School Experiences. *Journal of Autism and Developmental Disorders*, *49*(8), 3073–3088. http://dx.doi.org/10.1007/s10803-019-04022-z

Lashewicz, B., Boettcher, N., Lo, A., Shipton, L., & Parrott, B. (2018). Fathers raising children with autism spectrum disorder: stories of marital stability as key to parenting success. *Issues in Mental Health Nursing*, *39*(9), 786-

794.http://dx.doi.org/10.1080/01612840.2018.1466943

Lawson, W. B. (2020). Adaptive Morphing and Coping with Social Threat in Autism: An Autistic Perspective. *Journal of Intellectual Disability-Diagnosis and Treatment*, *8*(3), 519-526. http://dx.doi.org/10.6000/2292-2598.2020.08.03.29

Lecavalier, L., Smith, T., Johnson, C., Bearss, K., Swiezy, N., Aman, M.G., Sukhodolsky, D.G., Deng, Y., Dziura, J., & Scahill, L. (2017). Moderators of parent training for disruptive behaviors in young children with autism spectrum disorder. *Journal of Abnormal Child Psychology*, *45*(6), 1235-1245. http://dx.doi.org/10.1007/s10802-016-0233-x

Letzel, V., Pozas, M., & Schneider, C. (2020). Energetic students, stressed parents, and nervous teachers: A comprehensive exploration of inclusive homeschooling during the COVID-19 crisis. *Open Education Studies*, *2*(1), 159-170. https://doi.org/10.1515/edu-2020-0122

Lever, A. G., & Geurts, H. M. (2018). Is older age associated with higher self-and other-rated ASD characteristics?. *Journal of Autism and Developmental Disorders*, *48*(6), 2038-2051. http://dx.doi.org/10.1007/s10803-017-3444-2

Leveto, J. A. (2018). Toward a sociology of autism and neurodiversity. *Sociology Compass*, *12*(12), e12636. http://dx.doi.org/10.1111/soc4.12636

Liao, X., Lei, X., & Li, Y. (2019). Stigma among parents of children with autism: A literature review. *Asian Journal of Psychiatry*, *45*, 88-94. http://dx.doi.org/10.1016/j.ajp.2019.09.007

Lindsey, R. A., & Barry, T. D. (2018). Protective factors against distress for caregivers of a child with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(4), 1092-1107. http://dx.doi.org/10.1007/s10803-017-3372-1

Livingston, L. A., Colvert, E., Social Relationships Study Team, Bolton, P., & Happé, F. (2019). Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, *60*(1), 102-110. http://dx.doi.org/10.1111/jcpp.12886

Locke, J., Olsen, A., Wideman, R., Downey, M. M., Kretzmann, M., Kasari, C., & Mandell, D. S. (2015). A tangled web: the challenges of implementing an evidence-based social engagement intervention for children with autism in urban public school settings. *Behavior Therapy*, *46*(1), 54-67. http://dx.doi.org/10.1016/j.beth.2014.05.001

Lorenz, T., Frischling, C., Cuadros, R., & Heinitz, K. (2016). Autism and overcoming job barriers: Comparing job-related barriers and possible solutions in and outside of autism-specific employment. *PloS one*, *11*(1), e0147040. http://dx.doi.org/10.1371/journal.pone.0147040

Lounds Taylor, J., Adams, R. E., & Bishop, S. L. (2017). Social participation and its relation to internalizing symptoms among youth with autism spectrum disorder as they transition from high school. *Autism Research*, *10*(4), 663-672. http://dx.doi.org/10.1002/aur.1709

Love, A. M., Findley, J. A., Ruble, L. A., & McGrew, J. H. (2020). Teacher Self-Efficacy for Teaching Students with Autism Spectrum Disorder: Associations with Stress, Teacher Engagement, and Student IEP Outcomes Following COMPASS

Consultation. *Focus on Autism and Other Developmental Disabilities*, *35*(1), 47-54. http://dx.doi.org/10.1177/1088357619836767

Love, A. M., Toland, M. D., Usher, E. L., Campbell, J. M., & Spriggs, A. D. (2019). Can I teach students with Autism Spectrum Disorder?: investigating teacher self-efficacy with an emerging population of students. *Research in Developmental Disabilities*, *89*, 41-50. http://dx.doi.org/10.1016/j.ridd.2019.02.005

Lovell, B., & Wetherell, M. A. (2019). Affiliate stigma, perceived social support and perceived stress in caregivers of children with autism spectrum disorder: A multiple mediation study. *Archives of Psychiatric Nursing*, *33*(5), 31-35. https://doi.org/10.1016/j.apnu.2019.08.012

Lugo-Marín, J., Gisbert-Gustemps, L., Setien-Ramos, I., Español-Martín, G., Ibañez-Jimenez, P., Forner-Puntonet, M., Arteaga-Henriquez, G., Soriano-Dia, A., Duque-Yemail, J. D., & Ramos-Quiroga, J. A. (2021). COVID-19 pandemic effects in people with Autism Spectrum Disorder and their caregivers: Evaluation of social distancing and lockdown impact on mental health and general status. *Research in Autism Spectrum Disorders*, *83*, 101757. https://doi.org/10.1016/j.rasd.2021.101757

Lunsky, Y., Hastings, R. P., Weiss, J. A., Palucka, A. M., Hutton, S., & White, K. (2017). Comparative effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders*, *47*(6), 1769-1779. http://dx.doi.org/10.1007/s10803-017-3099-z

MacLeod, K. (2017). "I Should Have Big Dreams": A Qualitative Case Study on Alternatives to Guardianship. *Education and Training in Autism and Developmental Disabilities, 52*(2), 194-207. https://www.jstor.org/stable/26420390

Maenner, M. J., Shaw, K. A., & Baio, J. (2020). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance Summaries*, *69*(4), 1. http://dx.doi.org/10.15585/mmwr.ss6904a1

Maiano, C., Normand, C. L., Salvas, M. C., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta□analysis. *Autism Research*, *9*(6), 601-615. http://dx.doi.org/10.1002/aur.1568

Mandy, W., & Lai, M. C. (2017). Towards sex-and gender-informed autism research. *Autism*, *21*(6), 643-645. http://dx.doi.org/10.1177/1362361317706904

Mandy, W., Murin, M., Baykaner, O., Staunton, S., Cobb, R., Hellriegel, J., Anderson, S., & Skuse, D. (2016). Easing the transition to secondary education for children with autism spectrum disorder: An evaluation of the Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD). *Autism*, *20*(5), 580-590. http://dx.doi.org/10.1177/1362361315598892

Mapelli, L. D., Barbieri, M. C., Castro, G. V. D. Z. B., Bonelli, M. A., Wernet, M., & Dupas, G. (2018). Child with autistic spectrum disorder: care from the family. *Escola Anna Nery*, *22*(4). http://dx.doi.org/10.1590/2177-9465-ean-2018-

0116

Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging, 40*(6), 535-557. http://dx.doi.org/10.1177/0164027517717044

Marsack, C. N., & Hopp, F. P. (2019). Informal support, health, and burden among parents of adult children with autism. *The Gerontologist*, *59*(6), 1112-1121. http://dx.doi.org/10.1093/geront/gny082

Marsack-Topolewski, C. N., & Church, H. L. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *124*(2), 145-156. http://dx.doi.org/10.1352/1944-7558-124.2.145

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience Bulletin*, *33*(2), 183-193. http://dx.doi.org/10.1007/s12264-017-0100-y

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, *11*(3), article 8. https://doi.org/10.17169/fqs-11.3.1428

Maxwell, J. A. (2012). *Qualitative research design: An interactive approach* (Vol. 41). Sage publications.

McDonnell, T. E., Bail, C. A., & Tavory, I. (2017). A theory of resonance. *Sociological Theory*, *35*(1), 1-14. http://dx.doi.org/10.1177/0735275117692837

McGhee Hassrick, E., Sosnowy, C., Graham Holmes, L., Walton, J., & Shattuck, P. T. (2020). Social Capital and Autism in Young Adulthood: Applying Social Network Methods to Measure the Social Capital of Autistic Young Adults. *Autism in Adulthood*. https://doi.org/10.1089/aut.2019.0058

McHale, S. M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of youth with autism spectrum disorders: Theoretical perspectives on sibling relationships and individual adjustment. *Journal of Autism and Developmental Disorders*, *46*(2), 589-602. http://dx.doi.org/10.1007/s10803-015-2611-6

Mead, G. H. (1934). *Mind, self and society* (Vol. 111). University of Chicago Press.

Meleady, J., Clyne, C., Braham, J., & Carr, A. (2020). Positive contributions among parents of children on the autism spectrum: A Systematic review. *Research in Autism Spectrum Disorders*, *78*, 101635. https://doi.org/10.1016/j.rasd.2020.101635

Milan, M., & Nicolas, D.B. (2017). Examining transitions from youth to adult services for young persons with autism. *Social Work in Health Care, 56*(7), 636-648. https://doi.org/10.1080/00981389.2017.1318800

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, *25*(9), 1212-1222. http://dx.doi.org/10.1177/1049732315588501

Nathenson, R. A., & Zablotsky, B. (2017). The transition to the adult health care system among youths with autism spectrum disorder. *Psychiatric Services*, *68*(7), 735-738. http://dx.doi.org/10.1176/appi.ps.201600239

National Institute of Health (2019). Http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-19-100.html

Nevill, R. E., Lecavalier, L., & Stratis, E. A. (2018). Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. *Autism*, *22*(2), 84-98. https://doi.org/10.1177%2F1362361316677838

Nicholas, D. B., Zwaigenbaum, L., Zwicker, J., Clarke, M. E., Lamsal, R., Stoddart, K. P., Carroll, C, Muskat, B., Spoelstra, M., & Lowe, K. (2018). Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*, *22*(6), 693-702. https://doi.org/10.1177/1362361317702507

National Institute of Health, (2018). https://www.ninds.nih.gov/disorders/patient-caregiver-education/fact-sheets/autism-spectrum-disorder-fact-sheet

Niles, G. Y., & Monaco, E. A. H. (2019). Privilege, Social Identity and Autism: Preparing Preservice Practitioners for Intersectional Pedagogy. *DADD Online*, 112. http://www.daddcec.com/uploads/2/5/2/0/2520220/doj_6_2019_final.pdf#page=116

Noon, E. J. (2018). Interpretive phenomenological analysis: An appropriate methodology for educational research. *Journal of Perspectives in Applied Academic Practice| Vol*, *6*(1). http://dx.doi.org/10.14297/jpaap.v6i1.304

Nord, D. K., Stancliffe, R. J., Nye-Lengerman, K., & Hewitt, A. S. (2016). Employment in the community for people with and without autism: A comparative analysis. *Research in Autism Spectrum Disorders*, *24*, 11-16.

http://dx.doi.org/10.1016/j.rasd.2015.12.013

Norlyk, A., & Harder, I. (2010). What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies. *Qualitative Health Research*, *20*(3), 420-431. http://dx.doi.org/10.1177/1049732309357435

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), https://doi.org/10.1177%2F1609406917733847

Nunes, A. S., Vakorin, V. A., Kozhemiako, N., Peatfield, N., Ribary, U., & Doesburg, S. M. (2020). Atypical age-related changes in cortical thickness in autism spectrum disorder. *Scientific Reports*, *10*(1), 1-15. http://dx.doi.org/10.1038/s41598-020-67507-3

Nuske, H. J., Hedley, D., Tseng, C. H., Begeer, S., & Dissanayake, C. (2018). Emotion regulation strategies in preschoolers with autism: Associations with parent quality of life and family functioning. *Journal of Autism and Developmental Disorders*, *48*(4), 1287-1300. http://dx.doi.org/10.1007/s10803-017-3391-y

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. *Work*, *56*(2), 345-355. http://dx.doi.org/10.3233/WOR-172492

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, *12*, 745-762. https://doi.org/10.2147/ndt.s100634

Oswald, T. M., Winder-Patel, B., Ruder, S., Xing, G., Stahmer, A., & Solomon, M. (2018). A pilot randomized controlled trial of the ACCESS program: A group intervention to improve social, adaptive functioning, stress coping, and self-determination outcomes in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(5), 1742-1760. http://dx.doi.org/10.1007/s10803-017-3421-9

Pallathra, A. A., Cordero, L., Wong, K., & Brodkin, E. S. (2019). Psychosocial interventions targeting social functioning in adults on the autism spectrum: a literature review. *Current Psychiatry Reports*, *21*(1), 5. http://dx.doi.org/10.1007/s11920-019-0989-0

Pandey, S., & Sharma, C. (2018). Perceived burden in caregivers of children with autism spectrum disorder in Kathmandu valley. *Journal of Nepal Health Research Council*, *16*(2), 184-189. http://dx.doi.org/10.3126/jnhrc.v16i2.20308

Panicker, A., Basu, K., & Chung, C. F. (2020). Changing Roles and Contexts: Symbolic Interactionism in the Sharing of Food and Eating Practices between Remote, Intergenerational Family Members. *Proceedings of the ACM on Human-Computer Interaction*, *4*(CSCW1), 1-19. http://dx.doi.org/10.1145/3392848

Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2019). Systematic review of the relationship between autism stigma and informal caregiver mental health. *Journal of Autism and Developmental Disorders*, *49*(4), 1665-1685. http://dx.doi.org/10.1007/s10803-018-3835-z

Papay, C., Grigal, M., Hart, D., Kwan, N., & Smith, F. A. (2018). Predictors of inclusive course enrollments in higher education by students with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *56*(6), 458-470. https://doi.org/10.1352/1934-9556-56.6.458

Paradiz, V., Kelso, S., Nelson, A., & Earl, A. (2018). Essential self-advocacy and transition. *Pediatrics*, *141*(Supplement 4), S373-S377. http://dx.doi.org/10.1542/peds.2016-4300P

Parish, S. L., Thomas, K. C., Williams, C. S., & Crossman, M. K. (2015). Autism and families' financial burden: the association with health insurance coverage. *American Journal on Intellectual and Developmental disabilities*, *120*(2), 166-175. http://dx.doi.org/10.1352/1944-7558-120.2.166

Parish-Morris, J., Liberman, M.Y., Cieri, C., Herrington, J.D., Yerys, B.E., Bateman, L., Donaher, J., Ferguson, E., Pandey, J., & Schultz, R.T. (2017). Linguistic camouflage in girls with autism spectrum disorder. *Molecular Autism*, *8*(1), 48. http://dx.doi.org/10.1186/s13229-017-0164-6

Park, S.H., Song, Y.J.C., Demetriou, E.A., Pepper, K.L., Norton, A., Thomas, E.E., Hickie, I.B., Hermens, D.F., Glozier, N., & Guastella, A.J., (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism*, *23*(7), 1675-1686. http://dx.doi.org/10.1177/1362361318823925

Parker, M. L., & Molteni, J. (2017). Structural family therapy and autism spectrum disorder: Bridging the disciplinary divide. *The American Journal of Family Therapy*, *45*(3), 135-148. http://dx.doi.org/10.1080/01926187.2017.1303653

Patra, S., & Patro, B. K. (2019). Affiliate stigma among parents of children with autism in eastern India. *Asian Journal of Psychiatry*, *44*, 45-47. http://dx.doi.org/10.1016/j.ajp.2019.07.018

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice (4th ed.).* SAGE.

Pellicano, L., Bölte, S., & Stahmer, A. (2018). The current illusion of educational inclusion. *Autism: the International Journal of Research and Practice*, *22*(4), 386-387. http://dx.doi.org/10.1177/1362361318766166

Pierce, K., Marinero, S., Hazin, R., McKenna, B., Barnes, C. C., & Malige, A. (2016). Eye tracking reveals abnormal visual preference for geometric images as an early biomarker of an autism spectrum disorder subtype associated with increased symptom severity. *Biological Psychiatry*, *79*(8), 657-666. http://dx.doi.org/10.1016/j.biopsych.2015.03.032

Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PloS one*, *12*(10), e0186536. http://dx.doi.org/10.1371/journal.pone.0186536

Płatos, M., & Pisula, E. (2019). Service use, unmet needs, and barriers to services among adolescents and young adults with autism spectrum disorder in Poland. *BMC Health Services Research*, *19*(1), 587. https://doi.org/10.1186/s12913-019-4432-3

Postorino, V., Gillespie, S., Lecavalier, L., Smith, T., Johnson, C., Swiezy, N., Aman, M.G., McDougle, C.J., Bearss, K., Andridge, R.R., & Vitiello, B. (2019).

Clinical correlates of parenting stress in children with Autism Spectrum Disorder and serious behavioral problems. *Journal of Child and Family Studies*, *28*(8), 2069-2077. http://dx.doi.org/10.1007/s10826-019-01423-7

Potter, C. A. (2016). ‘I accept my son for who he is–he has incredible character and personality’: fathers’ positive experiences of parenting children with autism. *Disability & Society*, *31*(7), 948-965. http://dx.doi.org/10.1080/09687599.2016.1216393

Preece, D., & Trajkovski, V. (2017). Parent education in autism spectrum disorder–a review of the literature. *Hrvatska revija za rehabilitacijska istraživanja*. http://dx.doi.org/10.31299/hrri.53.1.10

Prendeville, P., & Kinsella, W. (2019). The role of grandparents in supporting families of children with autism spectrum disorders: A family systems approach. *Journal of Autism and Developmental Disorders*, *49*(2), 738-749. http://dx.doi.org/10.1007/s10803-018-3753-0

Rai, D., Heuvelman, H., Dalman, C., Culpin, I., Lundberg, M., Carpenter, P., & Magnusson, C. (2018). Association between autism spectrum disorders with or without intellectual disability and depression in young adulthood. *JAMA network open*, *1*(4), e181465-e181465. http://dx.doi.org/10.1001/jamanetworkopen.2018.1465

Rakap, S., Jones, H. A., & Emery, A. K. (2015). Evaluation of a web-based professional development program (Project ACE) for teachers of children with autism spectrum disorders. *Teacher Education and Special Education*, *38*(3), 221-239.

http://dx.doi.org/10.1177/0888406414535821

Rattaz, C., Michelon, C., Roeyers, H., & Baghdadli, A. (2017). Quality of life in parents of young adults with ASD: EpiTED cohort. *Journal of Autism and Developmental Disorders*, *47*(9), 2826-2837. http://dx.doi.org/10.1007/s10803-017-3197-y

Ravitch, S. M., & Carl, N. M. (2016). Validity: Process, strategies, and considerations. *Qualitative research: Bridging the conceptual, theoretical, and methodological*, 185-214.

Ravitch, S. M., & Riggan, M. (2016). *Reason & rigor: How conceptual frameworks guide research*. Sage Publications.

Rayan, A., & Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. *Research in Developmental Disabilities*, *55*, 185-196. http://dx.doi.org/10.1016/j.ridd.2016.04.002

Recio, P., Molero, F., García-Ael, C., & Pérez-Garín, D. (2020). Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities*, *105*, 103737. https://doi.org/10.1016/j.ridd.2020.103737

Richard, A. A. (2017). Policing and human rights in Nigeria: Marxism and symbolic interactionism. *AGOGO: Journal of Humanities*, *3*, 76-84.https://doi.org/10.46881/ajh.v3i0.106

Robertson, A. E., Stanfield, A. C., Watt, J., Barry, F., Day, M., Cormack, M., & Melville,

C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders*, *46*, 8-18. http://dx.doi.org/10.1016/j.rasd.2017.11.006

Robinson, E., Hull, L., & Petrides, K. V. (2020). Big Five model and trait emotional intelligence in camouflaging behaviours in autism. *Personality and Individual Differences*, *152*, 109565. http://dx.doi.org/10.1016/j.paid.2019.109565

Robinson, S., Hastings, R. P., Weiss, J. A., Pagavathsing, J., & Lunsky, Y. (2018). Self-Compassion and Psychological Distress in Parents of Young People and Adults with Intellectual and Developmental Disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 454–458. http://dx.doi.org/10.1111/jar.12423

Rodriguez, G., Hartley, S. L., & Bolt, D. (2019). Transactional Relations between Parenting Stress and Child Autism Symptoms and Behavior Problems. *Journal of Autism and Developmental Disorders*, *49*(5), 1887–1898. http://dx.doi.org/10.1007/s10803-018-3845-x

Roulston, K. (2010). Considering quality in qualitative interviewing. *Qualitative Research*, *10*(2), 199-228. http://dx.doi.org/10.1177/1468794109356739

Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data* (3rd ed.). SAGE.

Ruble, L., McGrew, J. H., Wong, V., Adams, M., & Yu, Y. (2019). A preliminary study of parent activation, parent-teacher alliance, transition planning quality, and IEP and postsecondary goal attainment of students with ASD. *Journal of Autism and Developmental Disorders*, *49*(8), 3231-3243. http://dx.doi.org/10.1007/s10803-

019-04047-4

Rutherford, M., Singh-Roy, A., Rush, R., McCartney, D., O'Hare, A., & Forsyth, K. (2019). Parent focused interventions for older children or adults with ASD and parent wellbeing outcomes: A systematic review with meta-analysis. *Research in Autism Spectrum Disorders*, *68*, 101450. http://dx.doi.org/10.1016/j.rasd.2019.101450

Rynkiewicz, A., Schuller, B., Marchi, E., Piana, S., Camurri, A., Lassalle, A., & Baron-Cohen, S. (2016). An investigation of the 'female camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, *7*(1), 10. http://dx.doi.org/10.1186/s13229-016-0073-0

Salas, B. L., Rodríguez, V. Y., Urbieta, C. T., & Cuadrado, E. (2017). The role of coping strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with autism spectrum disorder. *Psicothema*, *29*(1), 55-60. https://doi.org/10.7334/psicothema2016.96

Saldaña, J. (2015). *The coding manual for qualitative researchers*. Sage.

Salleh, N. S., Abdullah, K. L., Yoong, T. L., Jayanath, S., & Husain, M. (2020). Parents' experiences of affiliate stigma when caring for a child with autism spectrum disorder (ASD): A meta-synthesis of qualitative studies. *Journal of Pediatric Nursing*, *55*, 174-183. http://dx.doi.org/10.1016/j.pedn.2020.09.002

Salvini, A. (2019). The methodological convergences between symbolic interactionism and constructivist grounded theory. *Przegląd Socjologii Jakościowej*, *15*(3), 10-29. http://dx.doi.org/10.18778/1733-8069.15.3.02

Samadi, S. A., Abdollahi-Boghrabadi, G., & McConkey, R. (2020). Parental satisfaction with caregiving among parents of children with autism spectrum disorders, attention deficit and hyperactivity, intellectual disabilities and typically developing. *Early Child Development and Care*, *190*(7), 1115-1122. https://doi.org/10.1080/03004430.2018.1518903

Samson, A. C., Hardan, A. Y., Lee, I. A., Phillips, J. M., & Gross, J. J. (2015). Maladaptive behavior in autism spectrum disorder: The role of emotion experience and emotion regulation. *Journal of Autism and Developmental Disorders*, *45*(11), 3424-3432. http://dx.doi.org/10.1007/s10803-015-2388-7

Sasson, N. J., & Morrison, K. E. (2019). First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers. *Autism*, *23*(1), 50-59. http://dx.doi.org/10.1177/1362361317729526

Scahill, L., Bearss, K., Lecavalier, L., Smith, T., Swiezy, N., Aman, M.G., Sukhodolsky, D.G., McCracken, C., Minshawi, N., Turner, K., & Johnson, C. (2016). Effect of parent training on adaptive behavior in children with autism spectrum disorder and disruptive behavior: Results of a randomized trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, *55*(7), 602-609. https://doi.org/10.1016/j.jaac.2016.05.001

Schlebusch, L., Dada, S., & Samuels, A. E. (2017). Family quality of life of South African families raising children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(7), 1966-1977. http://dx.doi.org/10.1007/s10803-017-3102-8

Schoen, S. A., Lane, S. J., Mailloux, Z., May‐Benson, T., Parham, L. D., Smith Roley, S., & Schaaf, R. C. (2019). A systematic review of ayres sensory integration intervention for children with autism. *Autism Research*, *12*(1), 6-19. http://dx.doi.org/10.1002/aur.2046

Schönfeld, P., Brailovskaia, J., Bieda, A., Zhang, X. C., & Margraf, J. (2016). The effects of daily stress on positive and negative mental health: Mediation through self-efficacy. *International Journal of Clinical and Health Psychology*, *16*(1), 1-10. http://dx.doi.org/10.1016/j.ijchp.2015.08.005

Schönfeld, P., Brailovskaia, J., Bieda, A., Zhang, X. C., & Margraf, J. (2016). The effects of daily stress on positive and negative mental health: Mediation through self-efficacy. *International Journal of Clinical and Health Psychology*, *16*(1), 1-10. https://doi.org/10.1016/j.ijchp.2015.08.005

Schuck, R. K., Flores, R. E., & Fung, L. K. (2019). Brief report: Sex/gender differences in symptomology and camouflaging in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(6), 2597-2604. http://dx.doi.org/10.1007/s10803-019-03998-y

Schuck, R. K., Flores, R. E., & Fung, L. K. (2019). Brief report: Sex/gender differences in symptomology and camouflaging in adults with autism spectrum disorder. *Journal of autism and developmental disorders*, *49*(6), 2597-2604. http://dx.doi.org/10.1007/s10803-019-03998-y

Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PloS one*, *12*(5), e0177607. http://dx.doi.org/10.1371/journal.pone.0177607

Scott, M., Milbourn, B., Falkmer, M., Black, M., Bölte, S., Halladay, A., Lerner, M., Taylor, J.L., & Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism*, *23*(4), 869-901. http://dx.doi.org/10.1177/1362361318787789

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. Teachers college press.

Shattuck, P. T., Garfield, T., Roux, A. M., Rast, J. E., Anderson, K., Hassrick, E. M., & Kuo, A. (2020). Services for Adults With Autism Spectrum Disorder: a Systems Perspective. *Current Psychiatry Reports, 22*(3), 13. http://dx.doi.org/10.1007/s11920-020-1136-7

Shattuck, P. T., Lau, L., Anderson, K. A., & Kuo, A. A. (2018). A national research agenda for the transition of youth with autism. *Pediatrics*, *141*(Supplement 4), S355-S361. http://dx.doi.org/10.1542/peds.2016-4300M

Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. *Anxiety, Stress, & Coping*, *31*(3), 277-290. https://doi.org/10.1080/10615806.2018.1442614

Shivers, C. M., Jackson, J. B., & McGregor, C. M. (2019). Functioning among typically developing siblings of individuals with autism spectrum disorder: A meta-analysis. *Clinical Child and Family Psychology Review*, *22*(2), 172-196. http://dx.doi.org/10.1007/s10567-018-0269-2

Shivers, C. M., Krizova, K., & Lee, G. K. (2017). Types of strain among family members of individuals with autism spectrum disorder across the lifespan. *Research in Developmental Disabilities*, *68*, 42-51. http://dx.doi.org/10.1016/j.ridd.2017.07.003

Shivers, C. M., Sonnier□Netto, L., & Lee, G. K. (2019). Needs and Experiences of Family Caregivers of Individuals With Autism Spectrum Disorders Across the Lifespan. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(1), 21-29. http://dx.doi.org/10.1111/jppi.12272

Shmulsky, S., Gobbo, K., & Donahue, A. (2015). Groundwork for Success: A College Transition Program for Students with ASD. *Journal of Postsecondary Education and Disability*, *28*(2), 235-241. https://files.eric.ed.gov/fulltext/EJ1074676.pdf

Shogren, K. A., Wehmeyer, M. L., Shaw, L. A., Grigal, M., Hart, D., Smith, F. A., & Khamsi, S. (2018). Predictors of self-determination in postsecondary education for students with intellectual and developmental disabilities. *Education and Training in Autism and Developmental Disabilities*, *53*(2), 146-159. https://eric.ed.gov/?id=EJ1179161

Sicherman, N., Loewenstein, G., Tavassoli, T., & Buxbaum, J. D. (2018). Grandma knows best: Family structure and age of diagnosis of autism spectrum disorder. *Autism*, *22*(3), 368-376. http://dx.doi.org/10.1177/1362361316679632

Šijaković, I., & Vilić, D. (2019). The construction of the self through symbolic interaction with the other in everyday life. *Politeia*, *9*(17), 81-106. http://dx.doi.org/10.5937/politeia0-19722

Sim, A., Cordier, R., Vaz, S., Netto, J., & Falkmer, T. (2017). Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder. *Developmental Neurorehabilitation*, *20*(2), 83-91. http://dx.doi.org/10.3109/17518423.2015.1069414

Siu, Q. K. Y., Yi, H., Chan, R. C. H., Chio, F. H. N., Chan, D. F. Y., & Mak, W. W. S. (2019). The Role of Child Problem Behaviors in Autism Spectrum Symptoms and Parenting Stress: A Primary School-Based Study. *Journal of Autism and Developmental Disorders*, *49*(3), 857–870. http://dx.doi.org/10.1007/s10803-018-3791-7

Snell-Rood, C., Ruble, L., Kleinert, H., McGrew, J.H., Adams, M., Rodgers, A., Odom, J., Wong, W.H., & Yu, Y. (2020). Stakeholder perspectives on transition planning, implementation, and outcomes for students with autism spectrum disorder. *Autism*, 1362361319894827. http://dx.doi.org/10.1177/1362361319894827

Sobeck, E. E., & Robertson, R. (2019). Perspectives on Current Practices and Barriers to Training for Paraeducators of Students with Autism in Inclusive Settings. *Journal of the American Academy of Special Education Professionals*, *131*, 151. https://eric.ed.gov/?id=EJ1254304

Soltanifar, A., Akbarzadeh, F., Moharreri, F., Soltanifar, A., Ebrahimi, A., Mokhber, N., & Naqvi, S. S. A. (2015). Comparison of parental stress among mothers and fathers of children with autistic spectrum disorder in Iran. *Iranian Journal of Nursing and Midwifery Research*, *20*(1), 93.

https://www.ijnmrjournal.net/text.asp?2015/20/1/93/149823

Sosnowy, C., Silverman, C., & Shattuck, P. (2018). Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, *22*(1), 29-39. http://dx.doi.org/10.1177/1362361317699585

Southward, J. D., & Kyzar, K. (2017). Predictors of competitive employment for students with intellectual and/or developmental disabilities. *Education and Training in Autism and Developmental Disabilities*, *52*(1), 26-37. https://www.jstor.org/stable/26420373

Spain, D., Mason, D., Capp, S. J., Stoppelbein, L., White, S. W., & Happé, F. (2021). "This may be a really good opportunity to make the world a more autism friendly place": Professionals' perspectives on the effects of COVID-19 on autistic individuals. *Research in Autism Spectrum Disorders*, *83*, 101747. https://doi.org/10.1016/j.rasd.2021.101747

Späth, E. M., & Jongsma, K. R. (2020). Autism, autonomy, and authenticity. *Medicine, Health Care and Philosophy*, *23*(1), 73-80. https://doi.org/10.1007/s11019-019-09909-3

Spiers, G. (2015). Choices and caring: experiences of parents supporting young adults with autism spectrum conditions as they move into adulthood. *Children and Society, 29*, 546-557. https://doi.org/10.1111/chso.12104

Stadnick, N. A., Stahmer, A., & Brookman-Frazee, L. (2015). Preliminary effectiveness of Project ImPACT: A parent-mediated intervention for children with autism spectrum disorder delivered in a community program. *Journal of Autism and*

Developmental Disorders, *45*(7), 2092-2104. http://dx.doi.org/10.1007/s10803-015-2376-y

Stanford, C. E., Hastings, R. P., Riby, D. M., Archer, H. J., Page, S. E., & Cebula, K. (2020). Psychological distress and positive gain in mothers of children with autism, with or without other children with neurodevelopmental disorders. *International Journal of Developmental Disabilities*, 1-6. https://doi.org/10.1080/20473869.2020.1812347

Stewart, M., Knight, T., McGillivray, J., Forbes, D., & Austin, D. W. (2017). Through a Trauma-Based Lens: A Qualitative Analysis of the Experience of Parenting a Child with an Autism Spectrum Disorder. *Journal of Intellectual & Developmental Disability*, *42*(3), 212–222. http://dx.doi.org/10.3109/13668250.2016.1232379

Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C. J., Dziobek, I., & Roepke, S. (2017). Romantic relationships and relationship satisfaction among adults with Asperger syndrome and high-functioning autism. *Journal of Clinical Psychology*, *73*(1), 113-125. http://dx.doi.org/10.1002/jclp.22319

Sugita, T. (2017). Current trends in psychological and educational approaches for training and teaching students with autism in California. *International Electronic Journal of Elementary Education, 9*(2), 307-316. https://www.iejee.com/index.php/IEJEE/article/view/159

Sung, C., Sánchez, J., Kuo, H. J., Wang, C. C., & Leahy, M. J. (2015). Gender differences in vocational rehabilitation service predictors of successful competitive employment for transition-aged individuals with autism. *Journal of Autism and Developmental Disorders*, *45*(10), 3204-3218. http://dx.doi.org/10.1007/s10803-015-2480-z

Szatmari, P., Georgiades, S., Duku, E., Bennett, T.A., Bryson, S., Fombonne, E., Mirenda, P., Roberts, W., Smith, I.M., Vaillancourt, T., & Volden, J. (2015). Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. *JAMA Psychiatry*, *72*(3), 276-283. http://dx.doi.org/10.1001/jamapsychiatry.2014.2463

Tavassoli, T., Miller, L. J., Schoen, S. A., Brout, J. J., Sullivan, J., & Baron-Cohen, S. (2018). Sensory reactivity, empathizing and systemizing in autism spectrum conditions and sensory processing disorder. *Developmental Cognitive Neuroscience*, *29*, 72-77. http://dx.doi.org/10.1016/j.dcn.2017.05.005

Tavassoli, T., Miller, L. J., Schoen, S. A., Brout, J. J., Sullivan, J., & Baron-Cohen, S. (2018). Sensory reactivity, empathizing and systemizing in autism spectrum conditions and sensory processing disorder. *Developmental Cognitive Neuroscience*, *29*, 72-77. https://doi.org/10.1016/j.dcn.2017.05.005

Taylor, J. L., & Henninger, N. A. (2015). Frequency and correlates of service access among youth with autism transitioning to adulthood. *Journal of Autism and Developmental Disorders*, *45*(1), 179-191. http://dx.doi.org/10.1007/s10803-014-2203-x

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, *19*(7), 785-793. http://dx.doi.org/10.1177/1362361315585643

Tekin-Iftar, E., Collins, B. C., Spooner, F., & Olcay-Gul, S. (2017). Coaching teachers to use a simultaneous prompting procedure to teach core content to students with autism. *Teacher Education and Special Education*, *40*(3), 225-245. http://dx.doi.org/10.1177/0888406417703751

Thibodeau, R., & Finley, J. R. (2017). On associative stigma: Implicit and explicit evaluations of a mother of a child with autism spectrum disorder. *Journal of Child and Family Studies*, *26*(3), 843-850. http://dx.doi.org/10.1007/s10826-016-0615-2

Thomas, K. C., Williams, C. S., deJong, N., & Morrissey, J. P. (2016). Examination of parent insurance ratings, child expenditures, and financial burden among children with autism: a mismatch suggests new hypotheses to test. *Pediatrics*, *137*(Supplement 2), S186-S195. http://dx.doi.org/10.1542/peds.2015-2851Q

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018). To be understood: transitioning to adult life for people with autism spectrum disorder. *PloS one*, *13*(3), e0194758. http://dx.doi.org/10.1371/journal.pone.0194758

Thompson-Hodgetts, S., Labonte, C., Mazumder, R., & Phelan, S. (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. *Research in Autism Spectrum Disorders*, *77*, 101598. http://dx.doi.org/10.1371/journal.pone.0194758

Thurm, A., Manwaring, S. S., Swineford, L., & Farmer, C. (2015). Longitudinal study of symptom severity and language in minimally verbal children with autism. *Journal* *of Child Psychology and Psychiatry*, *56*(1), 97-104. http://dx.doi.org/10.1111/jcpp.12285

Thye, M. D., Bednarz, H. M., Herringshaw, A. J., Sartin, E. B., & Kana, R. K. (2018). The impact of atypical sensory processing on social impairments in autism spectrum disorder. *Developmental Cognitive Neuroscience*, *29*, 151-167. http://dx.doi.org/10.1016/j.dcn.2017.04.010

Tonnsen, B. L., & Hahn, E. R. (2016). Middle school students' attitudes toward a peer with autism spectrum disorder: Effects of social acceptance and physical inclusion. *Focus on Autism and Other Developmental Disabilities*, *31*(4), 262-274. http://dx.doi.org/10.1177/1088357614559213

Torrado, J. C., Gomez, J., & Montoro, G. (2017). Emotional self-regulation of individuals with autism spectrum disorders: smartwatches for monitoring and interaction. *Sensors*, *17*(6), 1359. http://dx.doi.org/10.3390/s17061359

Totkova, Z. (2019). Symbolic Interactionism and the Perceived Style of Parenting. *Qualitative Sociology Review*, *15*(2), 172-184. http://dx.doi.org/10.18778/1733-8077.15.2.11

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative inquiry, 16*(10), 837-851. http://dx.doi.org/10.1177/1077800410383121

Tsang, K. K., & Jiang, L. (2018). Positive Emotional Experiences in Teaching, Teacher Identity, and Student Behaviors: A Symbolic Interactionist Perspective. *Schools*, *15*(2), 228-246. http://dx.doi.org/10.1086/699890

Tullis, C. A., & Seaman-Tullis, R. L. (2019). Incorporating Preference Assessment into Transition Planning for People with Autism Spectrum Disorder. *Behavior Analysis in Practice*, *12*(3), 727-733. http://dx.doi.org/10.1007/s40617-019-00353-6

Ung, D., Selles, R., Small, B. J., & Storch, E. A. (2015). A systematic review and meta-analysis of cognitive-behavioral therapy for anxiety in youth with high-functioning autism spectrum disorders. *Child Psychiatry & Human Development*, *46*(4), 533-547. http://dx.doi.org/10.1007/s10578-014-0494-y

Utzumi, F. C., Lacerda, M. R., Bernardino, E., Gomes, I. M., Aued, G. K., & Sousa, S. M. (2018). Continuity of care and the symbolic interactionism: a possible understanding. *Texto Contexto Enferm*, *27*(2), e4250016. http://dx.doi.org/10.1590/0104-070720180004250016

van Esch, L., O'Nions, L., Hannes, K., Ceulemans, E., Van Leeuwen, K., & Noens, I. (2018). Parenting early adolescents with autism spectrum disorder before and after transition to secondary school. *Advances in Neurodevelopmental Disorders*, *2*(2), 179-189. http://dx.doi.org/10.1007/s41252-018-0058-4

Van Eylen, L., Boets, B., Steyaert, J., Wagemans, J., & Noens, I. (2015). Executive functioning in autism spectrum disorders: Influence of task and sample characteristics and relation to symptom severity. *European Child & Adolescent Psychiatry*, *24*(11), 1399-1417. http://dx.doi.org/10.1007/s00787-015-0689-1

Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum*

Disorders, *23*, 36-49. http://dx.doi.org/10.1016/j.rasd.2015.11.008

Ventola, P., Lei, J., Paisley, C., Lebowitz, E., & Silverman, W. (2017). Parenting a child with ASD: Comparison of parenting style between ASD, anxiety, and typical development. *Journal of Autism and Developmental Disorders*, *47*(9), 2873-2884. http://dx.doi.org/10.1007/s10803-017-3210-5

Waizbard-Bartov, E., Yehonatan-Schori, M., & Golan, O. (2019). Personal growth experiences of parents to children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(4), 1330-1341. http://dx.doi.org/10.1007/s10803-018-3784-6

Walsh, E., Holloway, J., McCoy, A., & Lydon, H. (2017). Technology-aided interventions for employment skills in adults with autism spectrum disorder: a systematic review. *Review Journal of Autism and Developmental Disorders*, *4*(1), 12-25. http://dx.doi.org/10.1007/s40489-016-0093-x

Watling, R., & Hauer, S. (2015). Effectiveness of Ayres Sensory Integration® and sensory-based interventions for people with autism spectrum disorder: A systematic review. *American Journal of Occupational Therapy*, *69*(5), 6905180030p1-6905180030p12. http://dx.doi.org/10.5014/ajot.2015.018051

Wehman, P., Schall, C.M., McDonough, J., Graham, C., Brooke, V., Riehle, J.E., Brooke, A., Ham, W., Lau, S., Allen, J. & Avellone, L. (2017). Effects of an employer-based intervention on employment outcomes for youth with significant support needs due to autism. *Autism*, *21*(3), 276-290. http://dx.doi.org/10.1177/1362361316635826

Weitlauf, A. S., Sathe, N., McPheeters, M. L., & Warren, Z. E. (2017). Interventions targeting sensory challenges in autism spectrum disorder: a systematic review. *Pediatrics*, *139*(6). https://doi.org/10.1542/peds.2017-0347

Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability?. *Journal of Intellectual Disability Research*, *59*(3), 272-283. http://dx.doi.org/10.1111/jir.12136

Westbrook, J. D., Fong, C. J., Nye, C., Williams, A., Wendt, O., & Cortopassi, T. (2015). Transition services for youth with autism: a systematic review. *Research on Social Work Practice*, *25*(1), 10-20. http://dx.doi.org/10.1177/1049731514524836

White, D., Hillier, A., Frye, A., & Makrez, E. (2019). College students' knowledge and attitudes towards students on the autism spectrum. *Journal of Autism and Developmental Disorders*, *49*(7), 2699-2705. http://dx.doi.org/10.1007/s10803-016-2818-1

Whittenburg, H. N., Cimera, R. E., & Thoma, C. A. (2019). Comparing Employment Outcomes of Young Adults with Autism: Does Postsecondary Educational Experience Matter? *Journal of Postsecondary Education and Disability*, *32*, 159-172. https://eric.ed.gov/?id=EJ1228971

Wiener, R. C., Vohra, R., Sambamoorthi, U., & Madhavan, S. S. (2016). Caregiver burdens and preventive dental care for children with autism spectrum disorder, developmental disability and/or mental health conditions: national survey of CSHCN, 2009–2010. *Maternal and Child Health Journal*, *20*(12), 2573-2580.

http://dx.doi.org/10.1007/s10995-016-2083-0

Wigham, S., Barton, S., Parr, J. R., & Rodgers, J. (2017). A systematic review of the rates of depression in children and adults with high-functioning autism spectrum disorder. *Journal of Mental Health Research in Intellectual Disabilities*, *10*(4), 267-287. http://dx.doi.org/10.1080/19315864.2017.1299267

Williams, M. E., Hastings, R., Charles, J. M., Evans, S., & Hutchings, J. (2017). Parenting for Autism, Language, And Communication Evaluation Study (PALACES): protocol for a pilot randomised controlled trial. *BMJ Open*, *7*(2), e014524. http://dx.doi.org/10.1136/bmjopen-2016-014524

Williams, M., & Moser, T. (2019). The art of coding and thematic exploration in qualitative research. *International Management Review*, *15*(1), 45-55. https://doi.org/10.4135/9781849208574.n4

Wong, C. C., Mak, W. W., & Liao, K. Y. H. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, *7*(6), 1385-1395. http://dx.doi.org/10.1007/s12671-016-0580-2

Wong, J., Cohn, E. S., Coster, W. J., & Orsmond, G. I. (2020). “Success Doesn’t Happen in a Traditional Way”: Experiences of school personnel who provide employment preparation for youth with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *77*, 101631. http://dx.doi.org/10.1016/j.rasd.2020.101631

Wood, R. (2019). Autism, intense interests and support in school: From wasted efforts to shared understandings. *Educational Review*, 1-21.

http://dx.doi.org/10.1080/00131911.2019.1566213

Wood-Downie, H., Wong, B., Kovshoff, H., Mandy, W., Hull, L., & Hadwin, J. A. (2021). Sex/gender differences in camouflaging in children and adolescents with autism. *Journal of Autism and Developmental Disorders*, *51*(4), 1353-1364. https://doi.org/10.1007/s10803-020-04615-z

Wozniak, R. H., Leezenbaum, N. B., Northrup, J. B., West, K. L., & Iverson, J. M. (2017). The development of autism spectrum disorders: variability and causal complexity. *Wiley Interdisciplinary Reviews: Cognitive Science*, *8*(1-2), e1426. http://dx.doi.org/10.1002/wcs.1426

Yorke, I., White, P., Weston, A., Rafla, M., Charman, T., & Simonoff, E. (2018). The association between emotional and behavioral problems in children with autism spectrum disorder and psychological distress in their parents: a systematic review and meta-analysis. *Journal of Autism and Developmental Disorders*, *48*(10), 3393-3415. http://dx.doi.org/10.1007/s10803-018-3605-y

Zablotsky, B., Rast, J., Bramlett, M. D., & Shattuck, P. T. (2020). Health care transition planning among youth with ASD and other mental, behavioral, and developmental disorders. *Maternal and Child Health Journal*, 1-9. http://dx.doi.org/10.1007/s10995-019-02858-6

Zajic, M. C., McIntyre, N., Swain-Lerro, L., Novotny, S., Oswald, T., & Mundy, P. (2018). Attention and written expression in school-age, high-functioning children with autism spectrum disorders. *Autism*, *22*(3), 245-258. http://dx.doi.org/10.1177/1362361316675121

Zanazzi, S. (2018). Does Mainstreaming Work? Teachers' Perspectives on Inclusive Education. *International Journal of Learning, Teaching and Educational Research*, *17*(10), 55-69. http://dx.doi.org/10.26803/ijlter.17.10.4

Zeedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: The postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 37-48. http://dx.doi.org/10.1177/1088357614525435

Zhou, T., Wang, Y., & Yi, C. (2018). Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: Effects of self-esteem, shame and family functioning. *Psychiatry Research*, *264*, 260-265. http://dx.doi.org/10.1016/j.psychres.2018.03.071

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2017). Associations between executive functions and mental health outcomes for adults with autism spectrum disorder. *Psychiatry Research*, *253*, 360-363. http://dx.doi.org/10.1016/j.psychres.2017.04.023

Zuckerman, K.E., Lindly, O.J., Reyes, N.M., Chavez, A.E., Cobian, M., Macias, K., Reynolds, A.M. & Smith, K. A. (2018). Parent perceptions of community autism spectrum disorder stigma: Measure validation and associations in a multi-site sample. *Journal of Autism and Developmental Disorders*, *48*(9), 3199-3209. http://dx.doi.org/10.1007/s10803-018-3586-x

Appendix A: Interview Guide

Qualitative Interview Guide

Opening the Interview:

Thank you for participating in this research study. Your participation supports the need for more information about the parent experience as their child with Autism Spectrum Disorder (ASD) transitions to adulthood. All informed consent procedures have been approved by an Individual Review Board. Personal information generated from the interview data will be redacted or destroyed. You may stop the interview at any time and for any reason. You will only participate in one interview. Your responses and participation are completely confidential. Do you have any questions before we begin?

My tour questions will include:

1. Tell me about your family unit/make-up?
2. What drew you to participate in this research study?
3. Tell me more about your child with ASD who has transitioned to adulthood?
4. What does an average day consist of for you/your child?

Main Question:

5. What is your experience with community/school supports for your child with ASD?

Probing question:

6. How have these supports impacted you/your child?

Main Question:

7. What types of supports do you provide as a parent of a child with ASD?

Probing Question:

8. What are some challenges to parenting a child with ASD?
9. How has these challenges changed during the transitioning process?

Main Question:

10. What types of supports and services are available to you as a parent with a child diagnosed with ASD?

Probing question:

11. In what ways has access to services changed since your child has transitioned to adulthood?

Reword if necessary:

12. What do you think changed/stayed the same with supports and services as your child transitioned to adulthood?

Main Question:

13. How would you describe supports and services necessary for your child's success?

Probing Question:

14. Recall a time where services were successful or failed for your child and how you responded.
15. What are the financial, emotional, social, or leisure supports you provide to your child?
16. How has your child's needs changed?
17. How has your needs, as a parent, changed?

Closing Question:

I have learned so much about your personal story as a parent experiencing the transition to adulthood for your child. Is there anything else you would like to share before we end the interview?

Closing Script for the Interview:

Thank you for the rich amount of information that you shared regarding this important topic. Your efforts will provide much needed information regarding the parenting experience during their child’s transition to adulthood. If you remember something regarding the topic that you believe is important, please contact me (provide contact information). I will contact you once the data is completed to verify the results for accuracy. Once the study is completed, I will share the results. As a reminder, all personal information will be destroyed that was collected. Your identity will remain anonymous.

Appendix B: Transcript Example Evidence

P-10 programs just shut down….now we have to get her back where she was before COVID.

P-5 Covid caused a delay in services…and job training stopped.

P-8 …is not doing well without class, everything just shut down.

P-6 Everything just dropped off, she's declined and she seems depressed.

P-3 Covid stopped all activities and she was home with me all of the time.

P-4 They didn't go remote, they didn't do anything.

P-9 She won't do a lot when she's home alone.

P-6 She is declining at home.

P-1 She's home full time and not self-directing.

P-3 She did not understand the Zoom platform and couldn't see the other students on the screen.

P-3 She won't do anything independently….she was getting no therapies during covid.

P-3 IPad wasn't set up right to participate in classes.

P-5 Home schooling was very difficult, I couldn't figure anything out.

P-6 She seems depressed, disconnected.

P-4 We all work, …is home alone all day.

P-5 All IEPs were the same, not individual…..no communication with parents. Only college bound got services.

P-3 Never had any individual transition planning. They're not looking at what she can do. Nothing is individual.

P-1 It's all one size fits all. If your not that disabled you get less services.

P-1 Teachers didn't follow up and only certain programs were available.

P-6 they only offer one size fits all. Schools don't prepare kids.

P-8 Life skills program was great. But high school was horrible because mainstreaming didn't work. She couldn't keep up. Tutors weren't prepared.

P-9 She was too advanced for what was offered at school. They only focus on kids with greater needs.

P-10 Access of services is only available based on autism level. No child left behind is wrong. Some get left behind.

P-4 After graduation she did not want to go back again.p-10 A lot of kids bullied her

P-4 …she did not do well in inclusion classes.

P-4 …classes were too overwhelming.

P–5 I was on my own and unaware of programs, I had no clue….everything is up to me.

P3 -Found a consumer directed program, but I'm doing it on autopilot. I got her therapies, Ot, PT, Speech.

P-2 We found the waiver program and have home health aides.

P-6 Your on your own to find programs.

P-7 We found teams of people that helped with him and we had found very supportive teachers.

P-7 We found consumer directed and respite care. Service coordination and it's amazing.

P-4 …we had to find alternative programs to school.

P-8 We have to make sure everything is set up….we are trying to prepare her to be able to go on without us.

P-8 She's vulnerable…she needs assisted living. She's mature but not enough though. We have to leave lists everywhere.

P-9 She continues to be dependent on us for basic stuff. We are nervous about driving. She is vulnerable and she can be naïve.

P-10 We support her being in social situations. She goes to camp and is around other kids. We want her to get her license but we don't push. She's vulnerable.

P-5 Doesn't know how to financially support himself. We do money spending training. Wants to learn how to drive.

P-6…your on auto pilot.

P-1…I was on auto pilot just in the zone.

P-10 She doesn't get invited to parties. She has a hard time expressing herself. She has social anxieties….and she is a little awkward. Noise triggers her. Distractions. Autism doesn't make them adults at 18.

P-5 He doesn't get sarcasm. Groups exclude him.

P-3 She can't organize, can't remember things. Kids didn't know how to deal with her. She has a hard time with time elapse. Huge anxiety problem. Doesn't know anything about strangers. Huge anxiety problem.

P1- Needs help staying on topic. She has no insight. She only wants to focus on certain things like art. She cannot navigate new environment.

P-2 She can't effectively communicate.

P-6 She can't communicate easily. She's disconnected.

P-7 He cannot understand if you speak fast or rush.

P-8 Doesn't make a lot of friends. She obsesses when she gets something in her head. She has a hard time with transitions. She needs time to settle in a new situation. She needs repetition. She doesn't do well with people.

P-4 …very slow processing speed.

P-9 She will shut down if she is pushed. She has trouble with basic stuff. She has no motivation. Needs to pick up on social cues.

P-4 she would just sit down in the middle of the hallway and shut down. Could be the littlest thing that sets them off.

P-8…they want to be normal.

P-9 We used to go out. But it's been a negative impact on social situations.

P-10 We would blame each other and not communicate. Takes it's toll on marriage. We separated. But now we have grown together. Stressful to deal with. Counseling helped.

P-1 He is completely hands off. I do all of the kids stuff.

P-2 It was very stressful. Took a toll on our marriage. There was a huge impact. We needed to communicate better. We needed respite.

P-7 There was a humongous strain on marriage. We dealt with it really differently. Put a toll on relationship. I was the main caregiver.

P-8 Made my wife and I closer. Every marriage has stress. This is what we are dealt with.

P-4 …caused a strain. Was definitely a balancing act.

P-9 She continues to be dependent, she takes 2 college courses with many supports.

P-10 She is working on her CNA and will graduate in may. She wants to help, even in a volunteer capacity.

P-5 He doesn't know what he wants to do. Cannot financially support himself. Cannot drive yet.

P-3 She doesn't have any friends. She is regressing. She can't do anything independently.

P-1 Shes not quite up to snuff. She doesn't have her HS group. She is in college but only can do well in classes she likes like art. She gets tutoring help. She is naïve and vulnerable.

P-6 You only matter if your under 22. You feel discarded. Shes declined without services.

P-7 He did better once he left high school. He's flourishing with a part time job and a job coach.

P-8 She wants to live independently but cannot support herself financially. She needs assisted living program. She needs guidance.

P-4 They need to match staff and programs to kids needs. Be more sensitive to child's needs.

P-4 …develop student buddy system.

P-4…have college courses available with individual curriculums.

P-4 …need for parent support group.

P-10 …need trained teachers, quality clinicians.

P-10…need more funding for transition planning.

P-10 Organizations that bring parents together.

P-10…need a specialized driving school and more social groups.

P-10need the best of the best that understand the spectrum.

P-8 …need tutor programs in school and college.

P-8…smaller classrooms with trained teachers.

P-6…support group for moms, help us prepare for transitioning.

P-6… well trained staff and programs individualized for kids.

P-7…need transition planning earlier.

P-9…need for individualized programs.

P-5…need for driving schools for ASD.

P-5…peer support programs for kids transitioning.

P-3…more help up front learning the process of transitioning.

P-1 We need more specialized employment programs.