Beyond the cliff: Parent perspectives on achieving positive employment outcomes for their autistic young adult.

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When I started this doctoral degree in 2017, my eldest daughter was also graduating from high school. I distinctly remember my thoughts at that time: I have a little more time with one less child to take care of, and I knew I wanted to eventually get a PhD, and, if not now, when? In hindsight, starting this journey with a full-time job, three children still at home, and as a solo parent always felt like there was never enough gas in the tank. Throw in a pandemic, unexpected health challenges, and two (plus!) long years of being homebound, and I started to have serious doubts about finishing this work.

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Dedication

To, my son, Zachariah.

Abstract

The unemployment rate for autistic young adults after high school graduation is higher than for all other populations with disabilities. The Individuals with Disabilities Education Act (IDEA) requires transition planning as part of an individualized education plan (IEP) starting no later than age 16. There is evidence, however, that autistic individuals experience difficulty with the transition to adulthood and have numerous needs unmet by current educational and social service providers (Hagner et al., 2014). Research has suggested that the role of parents is of vital importance in creating pathways for their autistic child to successfully achieve adult outcomes, including competitive integrated employment (CIE). CIE is one of the desired outcomes of IEP/transition planning. The purpose of this qualitative, multiple case study was to explore how parents of autistic children helped them navigate post-school transition and obtain CIE. Two theories are thought to play a role in this process. Wigfield and Eccles' (2000) expectancy value theory was extended to parent expectations as contributors to CIE for their autistic children. In parallel, Barbara Fredrickson's broaden-and-build theory (2001) offers a conceptual framework to understand how positive parent expectations play a role in their child's achievement of goals and produces an iterative cycle of higher expectations and achievements. The study identified four closely related themes - the role, expectations, and advocacy of parents, inadequacy of comprehensive transition planning, access to knowledge and limited resources, and dogged determination - that described how parents in this study were able to help their children navigate a path to CIE. Findings have implications for different stakeholders, including other parents who are just beginning the transition process with their autistic child, school staff that support them, as well as social service providers. I also describe considerations for future research and a specific role for human resource development researchers and practitioners.

Keywords: competitive integrated employment, autism spectrum disorder, parent expectations, transition, adult outcomes, case study

Table of Contents

List of Tables

List of Figures

Chapter One

The Research Problem: Up Close and Personal

"Try everything."

Descartes, 1637

When my second child Zachariah was about 15 months old, I took him to see his pediatrician because he was not reaching age-appropriate milestones. I enjoyed Dr. Jaeger's candor immensely, but I was not as amused when she asked, "Do you think he might be autistic?" My response was a resounding "No!" and while I was not quite sure what autism was, I left angry and scared. But by the time Zachariah was two, I knew his development was delayed. Walking came late at 18 months, and he remained nonverbal; his attempts to communicate with us were through screaming. In an attempt to find things he would like to do, I bought a number of toys and books. His favorite toys were Lego blocks and even at two, he created impressive Lego structures. I called several agencies asking for help and early childhood family education (ECFE) staff came out to do an evaluation. This time there was no escaping the diagnosis. Zachariah was very firmly on "the spectrum" and would benefit from early interventions. The medical model of autism views it as a disability (Accessible Education Center, 2022), so I threw myself wholeheartedly into looking for a "cure", and being my son's advocate.

It has been two decades of finding or creating opportunities for my son. Despite living in a state with significant resources dedicated to students with disabilities (see, Minnesota Olmstead Plan, 2022), young autistic people experience multiple barriers before and after high school completion that limit their ability to gain work-related skills, explore careers, and develop networks that can lead to meaningful employment and competitive, integrated employment

(Wehman et al., 2018). Some barriers are related to the characteristics of autism itself, i.e., social, behavioral, and communication challenges, as well as co-occurring health and mental health conditions. Other barriers are systemic and include employment social service providers who lack the expertise in working with autistic populations, the stigma associated with autism, including limited vocational and job opportunities available to autistic populations, and lack of employer awareness in providing the appropriate and optimal job accommodations (Austin & Pisano, 2017; Johnson, 2022).

Preparation for employment after high school for autism spectrum disorder (autistic) youth must begin as early as possible (Wong et al., 2021). Autism's heterogenous nature, as well as any co-occurring health and mental health conditions, can mean that behavior and other support needs range widely from minor to very extensive (Anderson et al., 2021). Furthermore, the systems that provide support and care during and after high-school completion – educational programs, healthcare systems, government services such as county case management and vocational rehabilitation – remain siloed and underfunded, leaving autistic youth at a disadvantage in preparation for college and employment (United States Department of Health & Human Services, 2021).

Over the next decade, it is estimated that one million autistic youth will navigate high school transition, enter adulthood, and begin looking for employment (Johnson, 2022; Roux et al., 2015; Roux et al., 2019; Roux et al., 2021). Current estimates suggest that 85% of autistic adults remain unemployed or underemployed after high school graduation (Johnson, 2022; Roux et al., 2019). Those that are employed earn, on average, less than minimum wages (Roux et al., 2019) with 25% of people with disabilities living in poverty with average annual incomes less than $15,000 (Sawyer, 2016). These numbers highlight the urgency of the need to examine the long-term employment, career, and life outcomes for these and future cohorts (Hurley-Hanson et al., 2020).

Despite these barriers, some autistic adults have successfully navigated a siloed system to find competitive, integrated employment (CIE) (Kirby, 2016). It is suggested that CIE is "the gold standard of transition outcomes for students with disabilities" (Allison et al., 2019, p.5) and means that disability populations are entitled to earn the same wage and work in the same environment as those without disabilities (United States Department of Labor, n.d.). These successes are uncommon and parent participation and support in transition planning have been found to be differentiating factors contributing to successful outcomes (Chen et al., 2019; Wong et al., 2021). As a parent who is on a similar journey, this motivated me to pursue a study with the purpose of exploring how parents of autistic children have navigated a post-high school path to help their children successfully transition into adulthood and find CIE. Using first-person accounts, this study will also investigate the strategies they used, challenges they faced, and their children' successes from the parents' perspective.

Background

Autism Spectrum Disorder, commonly referred to as Autism, refers to a group of neurodevelopmental disabilities characterized by significant social, communication, and behavioral impairments in children and adults (Developmental Disabilities, 2022). The prevalence of autism in the United States is on the rise: in 2016, the Centers for Disease Control (CDC) estimated that about 1 in 59 children was identified with autism, as compared to 1 in 166 children in 2004, although early screening and better diagnostic criteria may have contributed to higher prevalence rates (Elder et al., 2017; McGuinness & Kim, 2020). Autism can be reliably diagnosed as early as age 18 months to two years, with earlier diagnosis critical in determining therapies and supports for children across their lifespan (Elder et al., 2017). Autism's spectrum disorder characterization (Zager & Wehmeyer, 2019) requires varied and often significant individuation to meet the needs of youth who have "different intellectual and functional abilities, disability levels, and social-communication skills" (Wong et al., 2021, p. 61).

There are a few prevalent models on how autism is currently viewed. The primary medical model considers autism a disorder of the human condition and mandates therapies, medication, and treatments to 'cure' it (Chown & Beardon, 2017; Mitra, 2018). According to the medical disease model, autism is categorized as a disability. In comparison, the social model of autism considers it a normal variation on the spectrum of human neurodevelopment and advocates for therapies to help increase functional capabilities, medication to help manage any co-occurring mental health conditions, and supports to live an independent, dignified life (Mitra, 2018). Similarly, the critical disability models view the disabled person as whole, and the social and physical environment as lacking the accommodations needed to fully participate. Autism self-advocates and critical disability scholars are working to center those perceptions using the concept of neurodivergence, which views human neurodevelopment as existing on a spectrum (Leysen et al., 2021). Neurodivergence refers to the "concept of accepting and accommodating atypical cognitive styles and personality types as valuable elements of human difference" (Silverman, 2012, p. 125). Throughout this dissertation, I will use the terms "autistic" and "neurodivergent" interchangeably to account for both, my own lack of knowledge *and* my growing awareness of the use of ableist language and perceptions of disability.

As my son moved from elementary to middle school and then high school, I became immersed in the world of special education annual individualized education program (IEP), testing, assessments, and therapies (United States Department of Education, n.d.). I learned that there are many services and research (therapeutic, behavioral, etc.) focusing on the needs of young children. Early interventions take advantage of the neuroplasticity of young children's brains, giving treatments a better chance of being effective in the longer term (United States Department of Health & Human Services, 2021). There are less abundant services and transition-age research that address the needs of autistic youth/young adults (Johnson, 2022). Additionally, employment services for this unique population are not individualized for autistic youth's strengths, interests, and functional limitations. Most importantly, I learned about the age limits associated with special education services and the lack of educational and employment opportunities available to people on the spectrum after age 21, referred anecdotally to by parents as, "falling off a cliff" (Roux et al., 2015, p. 8).

Parents' Contribution to Competitive, Integrated Employment

Research has long suggested that parent expectations are one of the strongest predictors of academic achievement throughout the school years (Froiland, 2021). For neurodivergent youth, research similarly suggests that the role of parents is central to the successful transition from school to adulthood (Wong et al., 2021; Burke et al., 2019; Burke et al., 2021) with family context (household income, parental support and expectations, parent education) contributing factors that predict positive social outcomes (Kirby et al., 2016). Parents have often been referred to as the "linchpins" of services for their autistic children (Burke et al., 2019, p. 514), and for many parents this effort to identify and coordinate services begins at diagnosis and continues well into their child’s adulthood. In addition to autistic individuals themselves, parents understand their child’s needs the best, and often coordinate therapies and supports to maximize skills development over time. Burke et al (2019) likens the role of parents to “brokers” (p. 519) who navigate complex disability services to procure support for their child.

In a series of focus groups with parents of autistic young adults, Thompson et al (2018) found that parents who advocated for their autistic child, helping them discover, nurture, and leverage their strengths, believed that their children could apply those skills in the right environment and be successful. The authors also found that success in one area, i.e., employment, had a ripple effect on success in other life areas. Parents in these focus groups defined ‘success’ using a variety of indicators, including three important domains: independent living, employment, and social connectivity. Kirby (2016) clarified, however, that parents of autistic youth have a nuanced definition of success based on “realistic expectations” (p. 1655) of what their neurodivergent child can or cannot do based on their needs and any co-occurring conditions. In her study of a subset of autistic youth (n = 1170) from the National Longitudinal Transition Study-2 (NLTS2), Kirby (2016) reported that parental expectations were a significant contributing factor in establishing positive transition outcomes for autistic individuals. Parents who are highly involved in their autistic child’s transition planning process do so with the expectation that their child will be involved in a real job in the community for real pay and benefits (Holmes et al, 2018; Kirby, 2016; Wehman et al., 2018). Wong and colleagues (2021) found that parental involvement in their child’s education and future planning is related to positive employment outcomes after school. Other studies (Chiang et al., 2012) report that family support in the form of financial incentives, daily praise, and maintenance of program contingencies was also related to successful vocational engagement.

In their study, Chiang et al (2012) found that annual household income and level of parent education were significantly associated with positive employment outcomes for their autistic youth. The role of household income is inconsistent across studies but is suggested to be related to exposure to various careers and career decision making among youth with disabilities (Holmes et al., 2018). Parents with higher socio-economic status are also able to afford alternative therapies and education outside of what is provided at school and through an individualized education plan (IEP). In fact, Chiang et al (2012) found that positive employment outcomes are 17 times greater for transition-age autistic youth from high income families compared with low-income families. This disparity underscores the importance of providing more support to low-income families with autistic youth.

Regarding the long-term role that parents play in their autistic child(ren)'s lives, Thompson, et al (2018) found that parents continue to be a major source of support and advocacy as their children move into adult life. In fact, it is largely due to parents' hard work and relentlessness that the careful scaffolding of supports, therapies, coordination of meaningful activities and prior work experiences for their child result in successful adult outcomes, including employment (Chen et al., 2019; Glanzman, 2010; Holmes et al., 2018; McDonald, 2014). Adult outcomes for autistic youth are inconsistent, but despite the important role evidenced by parents, only a handful studies have focused on the impact of their engagement on positive employment outcomes for their transition age youth (Burke et al., 2019).

Introduction to IEP/Transition Planning

The transition from high school to adulthood is an important developmental process for any young adult. It is especially important for young adults with disabilities as they often struggle with making the transition from high school to adulthood. The Individuals with Disabilities Education Act (IDEA) enacted requirements in 1990 addressing the transition of all youth with disabilities served through special education on an IEP. IDEA requires that starting no later than age 16 (or younger if appropriate), students with disabilities must have an individualized education plan (IEP) that focuses on transition, and includes goals in the adult domains of employment, postsecondary education/training, independent living, and community integration (Burke et al., 2019; Chen et al., 2015; Shogren & Plotner, 2012). Specifically, competitive integrated employment (CIE) is a desired post-school outcome for students with disabilities because employment plays an important role in promoting independence, life satisfaction and well-being, developing a sense of accomplishment, as well as important financial benefits (Wehman et al., 2012; Wehman et al., 2018).

The services in IEP/transition plans should take into consideration students' interests, preferences and strengths as well as the supports needed to help students achieve their desired post-school outcomes, with independent living, a meaningful social life, and employment the most commonly addressed outcomes(Johnson, 2020) What complicates this process is the heterogeneity of autism as a condition - no two autistic people are alike and each person may experience co-occurring health and mental health conditions such as social anxiety, oppositional defiant disorder, attention-deficit/hyperactivity disorder, and intellectual disability (Anderson et al., 2021; McGuiness & Kim, 2020; Roux et al., 2021). These conditions are also compounded with the external difficulties typically experienced by autistic populations at work, such as poor communication skills during interviews, poor social skills in interacting with co-workers, difficulty navigating workplace dynamics, and the stigma associated with autism, which include stereotyped and limited interests, and repetitive behaviors (Anderson et al., 2021; Austin & Pisano, 2017; Johnson, 2022; Roux et al., 2021). Unfortunately, the practice of transition planning falls short of the intention of the federal mandate and does not adequately bridge the gap between individual needs, available social services, and employment that fits the interests and abilities of the individual (Anderson et al., 2021). More detail on IEP/transition planning is included in Chapter Two.

Problem Statement

For all youth, the transition period between entering high school and graduation is critical in developing work-related skills and gaining the types of experiences that can facilitate future meaningful employment (Dean et al., 2021; McDonald, 2014). Parent and family support remain an important factor in school years, and is especially critical for autistic youth as they continue to require assistance navigating the movement from school-age to adult services. Adult service structures have complex eligibility criteria, and it is often the parent and family caregivers who must bridge the supports between high school, transition, and adult life (Burke et al., 2019).

Compounding the problem of siloed education and adult social service systems (U.S. Department of Health & Human Services, 2017) is the limited state of autism research. Current autism research tends to focus on therapies, supports, and other interventions for young children, with limited research addressing transition, employment supports, and career guidance for autistic adults (Shattuck et al., 2020). Prior research on this topic has focused instead on direct associations between the predictors and employment outcomes, ignoring the role of moderators or mediators between predictors and employment outcomes (Wong et al., 2021). Autism's heterogenous presentation means that while individuation is one critical component to transition planning, "there is a high likelihood that the determinants of employment outcomes are complex and interrelated" (Wong et al., 2021, p. 61). The role of parents is one such moderator that can make a difference in successful transition planning.

Studies addressing the role of parents during transition often focus on life concerns, barriers to employment, and challenges related to the transition planning process. While these are important and valuable perspectives, a more positive approach is also needed. A positive framework in exploring the phenomenon of transition also focuses on strengths and opportunities, versus barriers to success. There is limited qualitative literature that explores how parents have helped their autistic children navigate the post-high school transition to adulthood and obtain CIE. Autism's heterogeneity also means that success in domains such as, employment, independence, and social connectivity is subjective. A qualitative approach that focuses on parents who have supported their child's transition into CIE, can enable a deeper understanding of this phenomena, and is well positioned to add to the developing body of literature on transitioning from post-school to employment.

Purpose of the Study

Despite a siloed support system of adult community services and dismal employment outcomes, there are autistic adults who have navigated the transition planning process to achieve competitive, integrated employment (CIE). Research has indicated one successful element of transition to adulthood is continued parental coordination and support in multiple aspects of their child's lives (McDonald, 2014). The purpose of this collective case study is to explore how parents of autistic children helped them navigate a post-school transition into adulthood and obtain CIE. Merriam advocates that research which focuses on "discovery, insight, and understanding from the perspectives of those being studied offers the greatest promise of making significant contributions" (1988, p. 3). Since parental support is instrumental to the success of autistic individuals, this study focused on listening to the stories of parents, how they navigated challenges during transition, successful strategies, and meaningful supports that have helped their children obtain CIE.

Research Design

This research project uses a case study approach as described by Merriam (1988) and Stake (1995) to paint a compelling portrait of the parental supports that make competitive, integrated employment a reality for autistic populations. Parents were selected using purposive sampling and a snowball approach. The data for this project consists of semi-structured interviews with parents of autistic young adults and an extensive literature review.

Case study designs have been used across a variety of disciplines and are a useful design when "the interest is in process rather than outcomes, in context rather than a specific variable, in discovery rather than confirmation" (Merriam, 1988, p. xii). Merriam (1998) also advocates for the use of case study research with "a problem identified from practice" (p. 44). The outcome I am exploring in this study – obtaining CIE, the successful and desired outcome of transition planning – is too multidimensional, complex, and diverse to explore using quantitative methods and requires the rich, thick descriptors typified by qualitative approaches. Cho et al (2022) advocate for the use of qualitative methodologies in HRD to "better capture and honor voices, experiences, and, meaning making of individuals…and communities" (p. 686). In particular, collective case studies that go beyond a single case study allow for innovation in HRD beyond traditional quantitative approaches and provide a stronger foundation for theoretical development through the use of within and cross-case analysis (Cho et al., 2022).

The use of this methodology was appropriate as it allowed me to explore parental perspectives about supports offered through the transition process, parental advocacy efforts, as well as others supports that were deemed important by parents in obtaining and maintaining CIE. I was drawn to this study and use of this methodology because as the parent of an autistic child, I hold a unique perspective in understanding this phenomenon. As a human resource development student (HRD), case study design approaches this complex process from a holistic and contextual perspective and can yield insights that are of foundational importance to HRD as it relates to employee development (Merriam, 1998).

Research Questions

The central research question guiding this study is: How do parents of autistic children help them navigate post-school transition and obtain competitive, integrated employment?

The following sub-questions helped focus information shared by parents on activities related to transition.

a. In what ways do expectations of parents inform the experience of their autistic child(ren) obtaining post-high school competitive, integrated employment?
b. What role did schools play in supporting the transition to post-high school employment?

c. What IEP/transition goals aligned with achieving competitive, integrated employment?

d. What challenges do parents report experiencing in helping their child achieve integrated competitive employment?

e. What types of formal (community service agency) and informal (friend, family) support did parents perceive as most essential to their child's success?

Significance of the Study

The successful transition into CIE for autistic youth has significance for multiple stakeholders. The high unemployment and underemployment rates in autistic populations' underscore the urgency to understand what supports and relationships can improve work trajectories for them. Thus, this research contributes to workforce development because it focuses on transition planning as it relates to successful employment in autistic populations, an area that has yet not been sufficiently explored in HRD. Neurodivergent populations themselves remain an untapped talent pool with well documented productivity and loyalty benefits (Austin & Pisano, 2017; Dreaver et al., 2019), making the findings of this study relevant to employers. Literature also highlights the "linchpin" (Burke et al., 2019) role that parents play, navigating the complexity of adult support services on behalf of their children, as well as ongoing coordination of services. It is surprising then, the limited support, training, and interventions directed at parents to achieve these outcomes. Workforce development staff and Vocational Rehabilitation service (VRS) staff play a pivotal role in helping autistic job seekers find and maintain employment. Unfortunately, many of them tend to be generalists and do not have the expertise to work with autistic populations. As one possible strategy, workforce development and other adult service delivery agencies could achieve higher rates of success for their clients by including both autistic job seekers and their parents in the planning process (Burke et al., 2019).

Beyond individual and employer needs, there is a larger societal benefit. Cultivating new narratives around disability and accommodations at work contribute to fostering truly inclusive workspaces. The findings of this study can be used to help agencies such as workforce development and employers expand their awareness of the distinct types of accommodations that help neurodivergent individuals participate in the world of work. By highlighting the myriad experiences autistic populations and their families have in seeking out work, previous poor job fit experiences, and “reasonable” accommodations that do more to prevent participation at work than create inclusive environments, there is potential to expand these findings to all employees that might be hesitant to disclose their own disabilities, creating a more inclusive environment for all employees.

The Role of Human Resource Development

The World Health Organization estimates that 15% of the global population has one or more disabilities; 80% of this number or ~785 million people are of working age (16-64) (Kwon, 2021; Procknow & Rocco, 2016). In parallel, a key research area in HRD is employee development. Within the United States, the unemployment rate for persons aged 16-64 with a disability is 10.8%, twice that of the population of the same age range without a disability (Disability employment statistics, n.d.). Unemployment statistics for Black and Brown persons with a disability are even higher as compared to their white peers: 9.9-15.8% as compared to 9.8% (Disability employment statistics, n.d.). Indisputably, adults with disabilities remain an underutilized segment of the labor pool (Procknow & Rocco, 2016). Hurley-Hanson and colleagues (2020) argue,

> There are individual, organizational, and societal costs when individuals with autistic are unemployed. These include the financial, social, and psychological costs of unemployment for individuals with autistic, their family, and caregivers. There are lost productivity costs for organizations facing labor and skills shortages that might be avoided by employing individuals with autistic. Finally, there are societal costs associated with supporting individuals with autistic who are unable to find and maintain employment. (p. 5)

Given HRD's humanistic leanings and research on other protected classes, such as race and gender, as the parent of a child with a disability and an HRD student, I believe it diminishes the integrity of HRD as a discipline to exclude disabilities from the conversations on diversity. From an employer perspective, there are federal tax benefits to hiring individuals with autistic, a workforce that is known to be productive and loyal, as well a greater sense of inclusivity that benefits the entire organization. From a community perspective, there are goodwill benefits and positive perceptions of the organization by current employees, potential employees, as well as the greater community (Hurley-Hanson et al., 2020).

Definitions and Key Terms

The following terms and definitions will be helpful throughout the rest of this dissertation.

Autism Spectrum Disorder/Autism (autistic) is a neurodevelopmental condition characterized by deficits in social interaction, difficulties in verbal and non-verbal communication, sensory problems, and restricted, repetitive patterns of behavior, interests or activities. Autism's spectrum diagnosis is a result of an amalgamation of all subtypes in the current version of the Diagnostical Statistical Manual, DSM-V, including autistic disorder, PDD-NOS, and Asperger syndrome (Cleary et al., 2023; Developmental Disabilities, 2022).

Competitive Integrated Employment (CIE) is the optimal employment outcome for students with disabilities. CIE is full-time or part-time work at minimum wage or higher, with wages and benefits similar to employees without disabilities performing the same work, and in environments that are fully integrated with co-workers without disabilities (Competitive Integrated Employment, n.d.).

Individualized Education Program (IEP) is both a process and written legal document that is the primary mechanism through which IDEA is implemented. Once eligibility has been established, IEP planning occurs annually and must consider the student's present level of educational performance, short and long-term measurable goals, special education and related services received, and mainstream activities that the student will or will not participate in.

Individuals with disabilities education act (IDEA) is a federal law that ensures a free, appropriate public education and related services to eligible children. Originally passed as the Education for Handicapped Children in 1975, the law was amended and reauthorized in 1990, 1997, and again in 2004 with significant revisions (Individuals with disabilities education act, 2022).

Intellectual Disability (ID) refers to an inability to learn at expected grade levels and function in daily life, and typically presents before the age of 18 years. Causes of ID include genetic abnormalities, problems during pregnancy or at birth, or because of a disease. ID can co-occur with autism but dual-diagnosis hovers around 30% of all diagnosed autism cases (Developmental Disabilities, 2022).

Neurodivergence is part of the social justice movement that advocates for a paradigmatic shift in viewing diverse neurological conditions, such as autism, as the result of normal variations in the human genome rather than a deficit, disorder, or impairment to be cured or treated. Some individuals with autistic who are IFL advocates, prefer to use the term neurodiverse to describe themselves (Hurley-Hanson, 2020).

Supports have been defined as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Arias et al., 2020, p. 2). Supports are, essentially, anything that enhances personal capacity or successful functioning, and enables people to live self-determined lives.

Transition Planning refers to a planning process that becomes part of the IEP once a student turns 16 or younger. IEP/transition planning consists of creating goals related to adult outcomes, such as independent living, post-secondary education and/or employment, and creating a meaningful social network. Implementation of these goals often involves establishing collaborative linkages between the school and other government and other social service agencies.

Organization of the Dissertation

This study explored how parents of autistic children helped them navigate post-school transition into adulthood and obtain CIE. Using cross-case analysis, findings revealed the essence of their collective experiences and how parents navigated structures and social systems to prepare their children for multiple successful adult outcomes and in particular, CIE. Through a series of in-depth interviews, the rich, thick, descriptions of experiences of five parents with autistic children were recorded and analyzed.

This dissertation is divided into six chapters. Chapter One outlines the study as well as my interest and background regarding autism and post- school employment. I also included the role of HRD in disability employment and introduced the term neurodivergent as an induction into Autism culture. In Chapter Two, I present the literature review as well as two possible theories that may be used to analyze the study, Wigfield and Eccles' (2000) expectancy value theory and Barbara Fredrickson's (2001) broaden-and-build theory. The literature review also contains sections on the following: the history of autism spectrum disorder, special education and related policies, transition planning, the role of community supports, including Vocational Rehabilitation, and the role of parents in supporting autistic individuals.

In Chapter Three I describe the methodology, research methods, and describe the role of researcher. I expand on my reasoning behind choosing a qualitative approach and why specifically, I selected a case study design. Other sections in this chapter detailed how I obtained Institutional Review Board permission, recruited and selected participants, data collection methods and analysis, and a discussion of trustworthiness and confidentiality. I presented summaries of parent narratives in Chapter Four, then described my findings in Chapters Five. I ended with Chapter Six by providing a discussion of my findings, and recommendations for parents with transition age autistic children and other stakeholders, and a call to HRD as an applied field, to broaden diversity research efforts to intentionally include disability, and find meaningful ways to work with a variety of stakeholders to increase the employment landscape for neurodivergent populations.

Chapter Two

Literature Review

Introduction

Chapter Two addresses existing knowledge and previously formed ideas about the complex phenomenon I am exploring through an extensive literature review. Autistic populations experience the highest rates of unemployment and underemployment as compared to other disability populations (Roux et al., 2019), however factors underlying poor postsecondary outcomes of autistic students are not well understood (Ruble et al., 2019). The literature review presented here hopes to unpack some of those underlying factors. I will first discuss the differences between the medical and social models of disability. Next, I explore the history of special education in general, and IEP/transition planning specifically in the United States school system. This chapter also introduces Vocational Rehabilitation Services (VRS) and its' historical underpinnings, examines the idealized intersection between VRS and IEP/transition planning, and takes a critical look at the gaps in planning and services after high school that cause so many autistic individuals to fall through the cracks. Finally, this chapter incorporates two theories, Wigfield and Eccles' expectancy value theory (2000), and Barbara Fredrickson's broaden-and-build theory (2001) that provide the foundation for discussing the role of parents in raising their autistic children, and analyzing different systems of influence on autistic individuals and their relationship to work.

Medical versus Social Models of Disability

The medical model views disability as a "defect" or "aberration" within the individual that must be fixed or cured for them to lead a normal life. This model of disability appeared in the mid-1800s with the emergence of asylums and institutions for people with intellectual, psychiatric, sensory, and physical disabilities. Institutionalization was a common practice which continued to dominate for more than one hundred plus years as a means of treating and caring for people with disabilities. This practice has declined or been eliminated in several states (e.g., Minnesota), however, it continues to prevail in other states.

The diagnostic criteria for understanding and identifying autism have changed multiple times over the past one hundred years, with criteria shifting from the domain of psychiatry to non-psychological frameworks to a neurological disorder with a strong genetic component (Silverman & Brosco, 2007). In 1911, psychiatrist Paul Eugen Bleuler who was also responsible for creating the concept of schizophrenia, subsequently came up with the concept of autism. He characterized autistic thinking as “infantile wishes to avoid unsatisfying realities and replace them with fantasies and hallucinations” (Evans, 2013, p. 4) and applied it to describe symptoms of the most severe cases of schizophrenia. Israel Kolvin’s research in 1971 however, separated the two conditions (Cleary et al., 2023; Evans, 2013); thus the conceptualization of autism as excessive hallucinations associated with schizophrenia evolved to mean a “complete lack of an unconscious symbolic life” (Evans, 2013, p. 4). Child psychiatrist Leo Kanner eventually mainstreamed use of the term ‘autistic’. In his seminal 1943 paper, ‘Autistic Disturbance of Affective Contact’, he outlined the case histories of eleven children, as well as observations of their behavior, and detailed histories from parents (Harris, 2018). Kanner concluded that autism was a highly variable condition and an innate disorder, thus laying the foundation for modern genetic studies.

The emergence of autism as a diagnosis continued to run parallel with "behavioral and medical approaches, sharing vocabularies, methodologies, and often, ideological commitments with them" (Silverman, 2012, p. 62). Autism has become one of the fastest growing disability diagnoses, and assessments remain, in large part with medical and psychological clinicians, focused on identifying autism characteristics and documenting observable behaviors deemed problematic (Cleary et al., 2023). This use of rigid rather than dynamic assessments continue to pathologize autistic behaviors, looking to treat, cure, or remove them (Fox, 2021).

The increase in autism's diagnostic and treatment evolution also parallels the closure of institutions and the growth of parental advocacy in seeking alternative diagnoses beyond mental retardation for their children (Evans, 2013; Silverman & Brosco, 2012). In her book, Understanding Autism, Chloe Silverman (2012) uses memoirs to describe the deep experience of parents in knowing, understanding, and raising their autistic children as *amateur expertise*. By situating this experience against that of medical science, she legitimizes parents' everyday knowledge of their children in autism discourses and reaffirms their critical role in their children's care.

The role that parents of autistic children play in their lives has been steeped in advocacy, and Cleary et al (2023) comment on the juxtaposition of parents' roles with the current evolution of how autism is perceived today. Parents' advocacy in seeking better access to services for their child has often catalyzed movement towards wider acceptance of autism as a culture rather than as a disorder (Cleary et al., 2023). This shift towards a social model of disability embraces a paradigm that argues disability is socially constructed and thus positions disability populations as lesser members of society (Liasidou, 2014). Other scholars offer the perspective that social models are a response to non-disabled people viewed as the norm and people with disabilities are less-than or inferior (Liasidou, 2014). Social and physical environments consist of systems, structures, and policies that embed ableism, into their design or framework. Ableism is described as prejudice and discrimination directed towards disabled people. Thus, social models of disability view the person as whole and part of the human experience, and the social and physical environment as lacking the accommodations needed to fully participate.

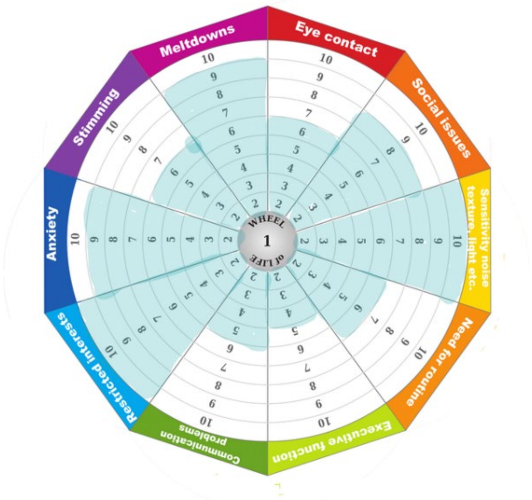
Advocacy, Identity, and Neurodivergence

Conversations around autism diagnosis have shifted from “person with autism” to “autistic person” to highlight the “needs, autonomy, and rights of autistic people” (Botha et al., 2021, p. 870). “Person with autism” is often referred to as “Person-first language” (PFL) and has been used to describe the “person before the disability” (Botha et al., 2021, p. 870; Procknow & Rocco, 2016). In comparison, autistic person falls under ‘Identity-first language’ (IFL) and emphasizes the inseparable nature of autism from the person (Botha et al., 2021). PFL stems from autism research and therapies that aim to treat autism, separate it from the person, and somehow cure it. IFL advocates for autism being an inherent part of a person’s identity and while there is acceptance that some therapies are designed to help autistic people function in mainstream society, “it is forgotten that autism *only* exists as a person” (Botha et al., 2021, p. 872), and the person and autism are inseparable from each other.

Autism is often referred to in terms of high versus low functioning, and thus perceptions of autism are also seen as binary. The terms “low” versus “high” functioning first appeared in the 1980s and were used in reference to autistic people with or without an intellectual disability (ID) (Alvares et al., 2020). I have often been asked if my son is low-functioning or high-functioning and up until a few years ago, I hedged my response and would say, he falls in the middle, reluctant to say low-functioning and categorize my son as having an ID, but knowing there were several areas of skills he needed more support with. Since then, I have learned that referring to autistic people in terms of functioning can be stigmatizing and may even predispose them to violence (Botha et al., 2021). This segmentation of high versus low fails to acknowledge the range of strengths and weaknesses of any individual (Silverman, 2012). Individuals referred to as high-functioning are assumed to have higher-than-average intelligence, may often have their needs minimized, and receive fewer supports than they need to be successful. Low-functioning is also synonymous with below-average intelligence, low productivity, and requiring assistance to do most tasks (Anderson et al., 2021).

Figure 1

Autism is Visualized as a Circular Spectrum.



Source: Claire Jack (Psychology Today, 2022, August 16)

Rather than thinking about autism linearly, it is best visualized as a wide circular spectrum based on several areas of functional needs. Figure 1 above depicts some of the core characteristics and needs related to autism. These needs can vary and might be related to language/communication, motor skills, executive functioning, sensory, and/or perception of situations. A better way to describe a person is according to their levels of needs and to say, ‘they need more/less support in this area’. Keeping this circular spectrum in mind, now when I am asked the functioning question about my son, my response is usually along the lines of, my son can take apart your computer and put it back together, but he won’t look twice before crossing the street, i.e., he has higher than average fine motor skills and a keen interest in technology, but a low ability to perceive safety.

Autism and Co-occurring Conditions

Intellectual Disability (ID)

The complexity of autism and its’ functional limitations have blurred boundaries with other similar conditions (Gardiner et al., 2018), such as attention-deficit disorder (ADHD), oppositional defiant disorder (ODD), and intellectual disability (ID) (Poling et al., 2012). ID can be characterized by “significant limitations in intellectual and adaptive functioning” (Howard et al., 2021, p. 307) with an IQ < 70. Adaptive functioning refers to difficulties with socialization, communication, and self-care (Gardiner et al., 2018). Seventy percent of autistic individuals have some level of ID while the remaining 30% have some disability (speech, behavior) other than cognitive dysfunction (Srivastava & Schwartz, 2014). The American Psychiatric Association (APA) (APA, 2023) rates ID from mild to profound based on the degree of intellectual and adaptive deficit in multiple domains (Cervantes & Matson, 2015). To determine educational and behavioral support interventions and match it to the appropriate interventions, parents must receive an accurate diagnosis for their child. In many cultural communities, reduced autism awareness leads to older age diagnoses and reduced opportunities for those early therapies and supports, and misdiagnosis of autistic behaviors with behavioral disorders, intellectual disabilities, and learning disabilities- especially for Black boys – persists (Aylward et al., 2021; Durkin et al., 2017; Howard et al., 2021; Kaiser et al., 2022). Cervantes and Matson (2015) state "the co-occurrence of autistic and ID has been associated with increased social and communication impairments, higher rates of restricted, repetitive behaviors, and the presence of more severe and more long-term challenging behaviors" (p. 3961).

Psychiatric Conditions

An autism diagnosis also carries an increased risk of psychiatric co-occurrences. Diagnosing and treating any co-occurring psychiatric disorders are complicated by the core characteristics of autism related to communicating feelings and emotions. The most commonly occurring disorders identified are bipolar disorder, anxiety, and clinically diagnosed depression (Kirsch et al., 2019). Psychiatric conditions, in turn, are also associated with disrupted functioning in social, academic, and work environments. Using a longitudinal, population-based birth cohort, Kirsch and colleagues (2019) found the association between being an autistic male and having co-occurring depression and anxiety was stronger than in autistic females. In that same study, they also found that autistic individuals experience greater rates of other mental health challenges, including ADHD and substance abuse.

Behavioral Challenges

Lack of social skills, communication deficits, maladaptive behaviors, and psychiatric co-occurrences also pose barriers to autistic individuals' ability to participate in and integrate into the community. Social and communication skills are necessary to navigate through a range of postsecondary environments, including workplaces, and for community inclusion in general (Walsh et al., 2018). As youth move through the special education system, persistent deficits in these skills not addressed through IEP goals, create a significant barrier to obtaining and maintaining employment. Chiang et al (2012) found that students with high social skills were 5.4 times more likely to participate in employment compared to those with low social skills.

Studies examining the impact of autistic -related communication challenges at work have found that individuals often have difficulty in reciprocal communication and understanding the communicative intent of others. Along with difficulty understanding verbal cues, autistic individuals struggle to understand facial expressions and tones of voice and handle job feedback. Conversely, they may ask too many unrelated non-work questions but conversely not know when to ask for help (Burt et al., 1991). Autistic individuals with or without ID often exhibit challenging and maladaptive behaviors such as self-injury, uncooperative behavior, aggression, or stereotypy (Lanovaz et al., 2017). These behaviors vary in terms of nature, frequency, duration, and intensity. As previously mentioned, the complex nature of autism and any co-occurring conditions make diagnosis of these conditions difficult. While many autistic individuals often receive two or more medications intended to ameliorate challenging behaviors related to a psychiatric condition, Poling and co-authors (2017) conclude that no drug significantly improves the core symptoms of autism, and some antipsychotic drugs come with their own serious side effects. While these represent just some of the difficulties that autistic individuals face in the workplace, in some cases they have resulted in termination of employment as well as further contribute to stigma around autism.

Special Education in the United States

Individuals with Disabilities Act

The historical roots of special education in the United States have evolved from segregation and institutionalization of people with disabilities to inclusion. The enactment of the first federal special education law, the Education for All Handicapped Children Act (EHA) in 1975, created the foundation for educational rights and access to public education programs for school-age children with disabilities. EHA, P.L. 94-142, guaranteed access to a free and appropriate public education (FAPE) to be conducted in the least restrictive environment (LRE) to all children with disabilities between the ages of 3-21(Johnson, 2020).

Family advocacy has always been at the forefront of change and has played an instrumental role in creating awareness of, and elevating the need for specialized education, and programming for children with disabilities. Prior to the passage of special education law in the United States, families were excluded from planning or placement decisions for their disabled child. Starting in the 1950's, family advocacy groups influenced early federal legislation to support early intervention and special education of children with disabilities (Johnson, 2020; Burke et al., 2021). The most recent federal special education legislation, the Individuals with Disabilities Education Act (IDEA) of 2004 continued to strengthen the FAPE and LRE provisions of earlier IDEA reauthorizations. Children may enter the special education system in multiple ways, but most commonly through a medical or psychological assessment to determine the extent to which their presenting disability interferes with learning (Aron & Loprest, 2012; Hebbeler & Spiker, 2016). Persistent racial disparities in autism diagnosis exist however, with Black and Hispanic children less likely than white peers to receive an autism diagnosis, leading to older age diagnosis and treatment services which are critical at younger ages (Hatfield et al., 2017).

IDEA requires that each eligible child must have an Individual Education Plan (IEP) that outlines how the school will meet the educational needs of the student. A well-developed IEP is both a legal document and the primary mechanism through which eligible children receive special education services in public schools. Effective IEP processes bring together the experiences and knowledge of parents, teachers, and other school staff to form the IEP team and create a plan that addresses the educational needs of the student as well any other eligible services that are related to educational performance.

IEPs must be written annually for each school year and include current educational performance, how the student's disability impacts their involvement and progress in the general education curriculum, annual measurable goals, steps to achieve appropriate levels of education as well as any modifications of programs and/or statewide testing, and transition service needs beginning at 16 (or younger if deemed appropriate by the IEP team). (A guide to the individualized education plan, 2019; Wong et al., 2018). Elementary and middle school IEPs tend to focus on school readiness skills, with high schools addressing work readiness skills (Nuske et al., 2019).

The link between successful transition planning and postschool outcomes cannot be emphasized enough. Recognizing its' importance, the evolution of EHA as related to transition planning is presented in Table 1.

Table 1

Individuals with Disabilities Act (IDEA): Amendments Related to Transition Planning

Year	**Description of Amendment**
1983	This amendment of the 1975 EHA was a response to the recognition that students receiving special education required more support as they moved from high school to employment and adult life, reinforcing the need for transition planning
1986	Amendments were added to support vocational programs for students with disabilities, as well as a new requirement that parents and the students with disabilities be more engaged in the special education process
1990	Congress changed the EHA to the Individuals with Disabilities Education Act (IDEA). IDEA is based on six pillars: development of an Individual Education Program (IEP), a free and appropriate public education, education that occurs in the least restrictive environment, appropriate and timely evaluation, parent and teacher involvement, and procedural safeguards to protect the rights of students with disabilities. This law was also instrumental in putting into law specific transition service requirements that must be followed for any student on an IEP beginning no later than age 16.
1997	In response to several studies documenting the lack of preparation for employment after high school, IDEA was reauthorized in 1997 to expand transition services and further strengthen the role of parents in the special education process. Transition planning continued to be required in student IEP development for students 16 years and older with the domains of education/training, employment, and independent living (as appropriate) to be addressed in planning for the future (Kraemer et al., 2022).
2004	The most recent reauthorization of IDEA placed an increased emphasis on student involvement in IEP/transition planning meetings, increased attention to postsecondary education as a post-school goal for students, and the development of measurable post-school goals that identifies the community agency supports necessary to achieve student’s goals (Johnson, 2020).

Source: C. Silveira

Transition Planning

Comprehensive transition planning (CTP) is part of the IEP process and "aims to equip students with the necessary skills and attributes needed to successfully enter into a post-school environment" (Chandroo et al., 2018, p. 8). The 2004 reauthorization of the Individuals with Disabilities Education Act (IDEA) defines transition services as "a coordinated set of activities for a child with a disability that is designed within a results-oriented process, focused on improving the academic and functional achievement of the child to facilitate movement from school to postschool activities" (Shogren & Plotner, 2012, p. 16). IEP/transition planning also includes referrals to post-high school services, supports, and other agencies that are critical to the success of students with disabilities (Curtiss et al., 2021). The goal of IEP/transition planning is to prepare youth with disabilities for adult life through activities and skill building that lead to positive outcomes in the domains of education/training, employment, and independent living, and for young autistic adults; thus IEP/transition planning is critical for success in adulthood (Kraemer et al., 2022).

Since its' 1990 reauthorization, IDEA has required that transition services become part of IEP planning discussions of students with disabilities beginning at age 16. IDEA 2004 included several provisions to strengthen the IEP/transition planning process related to student goals. First, the IEP/transition planning process must take into account the student's strengths as well as their preferences and interests; second, the IEP/transition planning team must consider goals for further education beyond high school in addition to employment and community living goals; third, postsecondary goals must be measurable to ensure that there is a means to determine the extent to which a student has achieved their goals; and fourth, the identification of the transition services (including courses of study) needed to assist students reaching their goals must also be included in the IEP (Johnson, 2020).

As the primary tool to prepare students with disabilities for post-high school life, transition planning has been met with repeated criticisms related to its' inadequacy to prepare students with disabilities for postschool life. Moreover, existing transition programs may not adequately address the unique needs of autistic students (Hatfield et al., 2017; Nuske et al., 2019). Kraemer et al. (2022) also report that IEP goals for autistic students often fail to integrate essential transition skills related to achieving critical adult domains. High-school environments are often disorienting, requiring movement from class to class, and have more fluidity than in elementary and middle school. For autistic students who value and require structure throughout their day, the dynamic and changing nature of high school can increase anxiety and mental health problems (Nuske et al., 2019).

While the 2004 IDEA regulations require that students are notified of, and invited to be part of the IEP/transition planning process, it does not specify that they must attend nor provide clarity about their role during the process (Chandroo et al., 2020; Johnson et al., 2020). Studies indicate that autistic youth may largely play a passive role during meetings (Johnson et al., 2020; Shogren & Plotner, 2012). Direct observation of stakeholder participation during IEP meetings suggests that youth spoke at meetings approximately 3% of the time in one study conducted by Martin et al. (2006). Using NLTS2 data, Griffin et al. (2014) examined the participation of students with autism spectrum disorders (autistic) during IEP/transition planning meetings. These researchers found that approximately 62% of their sample either did not attend the meeting or attended with very little participation. We know, however, that student participation in IEP transition planning meetings is an opportunity for students to self-direct and lead the planning process focused on their school and future post-school goals. Despite several decades of federal policy and empirical evidence from research demonstrating the capacity of young people with autism and other disabilities to actively participate in the IEP/transition planning process, progress has been slow and difficult to achieve (Johnson et al., 2020).

One possibility to increase the participation of autistic youth in the IEP/transition planning process is related to the development of self-determination (SD) skills. Self-determination theory offers a broad framework for the study of human motivation and personality and posits that all humans have three basic physiological needs – autonomy, competence, and relatedness (Deci & Ryan, 2008). For autistic youth, SD skills help them "make choices, set goals, and assist in problem-solving, self-monitoring, and self-advocating" which develop autonomy and independence (Cheak-Zamora et al., 2020, p. 605). While SD is a predictor of successful transition into adult life (Hatfield et al., 2017), low SD continues to be problematic for autistic students (Chandroo et al., 2020). Paradoxically, one contributing factor may be parents who may not provide their children with opportunities to develop life skills as they are accustomed to making most of the decisions for their child (Hatfield et al., 2017). Parents and schools should keep in mind however, that development of these skills before graduation is critical, as there are fewer opportunities to develop strong SD skills after that (Chandroo et al., 2020).

As part of increasing SD in disability populations, Wehmeyer suggests starting with strengthening choice-making skills (Bush & Tassé, 2017). Choice-making skills have been demonstrated in literature to have an association with employment, independent living, and community. Developing the capacity to make decisions for oneself allows autistic youth to expand their advocacy skills which also have a significant impact on personal functioning, including decreasing inappropriate behavior and increasing appropriate behavior. Choice-making skills should be promoted and offered in school at multiple points as they contribute to developing SD skills and a stronger transition process. Developing SD should be a priority in IEP/transition planning as it helps students identify their own needs, strengths, preferences, and interests regarding future life outcomes (Chandroo et al., 2020). One strategy suggested to achieve this in IEP/transition planning is to have a trusted person present whose role is to help students become more involved and identify choice-making opportunities. Another strategy is goal setting which presents each task as a series of manageable and actionable components appealing to the autistic person's need for structure (Hatfield et al., 2017).

Referencing the most recent 2020 U. S. Department of Education, Office of Special Education report, Kramer (2022) found transition planning compliance rate with IDEA requirements varied among states from 17% to 100%, suggesting that criticisms related to inadequacy of preparedness are not without merit. Multiple studies have demonstrated that many schools fail to meet minimum levels of compliance with the federal transition mandates, particularly in the areas of service coordination and interagency collaboration (Shogren & Plotner, 2012). Other factors related to compliance were student race/ethnicity, where being a Black student decreased the likelihood of full compliance with transition requirements (Kraemer et al., 2022). In using data from the National Longitudinal Transition study-2 (NLTS-2), Shogren and Plotner (2012) found that only 66% of autistic students had an IEP that specifically linked the student's course of study to transition goals. Unfortunately, even for schools compliant with

IDEA requirements, compliance does not equate to high quality (Kraemer et al., 2022). Nevertheless, there is sufficient evidence that indicates a positive relationship between transition planning that incorporates IDEA requirements and post-school outcomes (Kraemer et al., 2022; Shogren & Plotner, 2012).

The Role of Parents

Throughout history, parental advocacy that aims to improve the lives of their children has often been the impetus spurring political action and systemic change. The case is no different for special education, where the role of parental participation, and their ensuing advocacy has played a key role in guaranteeing students with disabilities the right to a free appropriate public education (Burke et al., 2021). Advocacy does not stop at high-school education; for autistic individuals, prolonged and vigilant family advocacy is associated with improvements in vocational engagement over time (Nicholas et al., 2017). Similarly, Ruble (2019) recognizes that parent-related variables, such as parental expectations, socio-economic status, and parent level of education influence advocacy, and are mediating factors between successful transition planning and positive postsecondary outcomes.

Parents and students themselves should be viewed as schools' partners in planning education and post-high school goals for their neurodivergent child (Johnson et al., 2020). The strengths of the parent-special education alliance bring value to the IEP/transition planning process (Ruble et al., 2019). Nuske et al. (2019) found that dynamic school-home partnerships are critical to promoting positive outcomes for students. It is recognition of the strength of those partnerships that has led to EHA's 1975 and amendments in 1986 to mandate parent participation. IDEA requires that students and their families be an integral part of the transition planning process (Burke et al., 2021). Unfortunately, families and students are often disenfranchised at various stages of the transition planning process, leading to dissatisfaction on the part of families, and contributing to poor post-school outcomes for students (Hagner et al., 2014). In response, person-centered planning has emerged as an approach that centers the needs of the student and resources the family can contribute (financial, emotional, etc.), and aims to empower individuals to "to plan their life, find their voice, and work toward reaching their goals" (Person-Centered Planning, 2022). Person-centered planning emphasizes a holistic exploration of the individual's strengths and interests, tailoring the assessment to individuals with different learning styles. Research also indicates that person-centered planning is designed to produce change at both the individual and the systems level.

Ruble et al (2019) outlined several family-level factors leading to successful employment of autistic individuals after graduation: household income, parental education, family expectations, and parental involvement. Chiang et al. (2012) indicate that autistic students from lower-income families (<$25,000 USD) and lower family education levels are at greater risk for poorer employment participation after high school. Nuske et al. (2019) demonstrated similar outcomes with children from low-income families at risk of poor transition outcomes. Kramer et al (2022) found that family involvement with IEP/transition planning varies according to student and family race/ethnicity, with decreased involvement observed for Black and Latinx students with IEPs. Hirano et al. (2018) report that non-White families and lower incomes families experience lower satisfaction with transition planning involvement. Nuske's (2019) study synthesizing difficulties and strategies experienced by autistic students, their parents, and teachers, found that parent characteristics related to family concerns, stress and anxiety cultural differences, and language barriers enhanced difficulty with the transition process. Lower income parents especially, may have increased demands on their time and emotional resources, limiting their ability to being engaged in transition planning for their young adult (Hirano et al., 2018). For students whose home language is not English, decreased involvement may be due to parents' inability to read or understand the paperwork involved with IEP/transition planning (Lusa & Oahn, 2020). Special education documents are often written at a ninth-tenth grade reading level and may contain extensive educational jargon (Burke et al., 2021; Hirano et al., 2018). Parental participation in IEP planning is required through IDEA and yet when procedural safeguards require a college or professional reading level (Burke et al., 2021), this puts parents with less education as well as English as a second language parents at a disadvantage and unable to effectively advocate for their autistic child. Perceptions of decreased parental involvement from the IEP/transition planning team may also manifest in lower quality plans (Hirano et al., 2018).

For transition age youth stuck between school-aged and adult-service worlds (Burke et al., 2019), parents must often balance the need to promote independence and self-determination while continuing to advocate for services that make independence possible (Bianco et al., 2009). In other instances, transition planning is not aligned with the values of families from other cultures, and places increased emphasis on Western values of independence and autonomy (Hirano et al., 2018). IEP/transition planning for families with autistic youth is often fraught with frustration, feelings of helplessness at the need to now navigate adult support services, and increased uncertainty about their children's future (Burke et al, 2019; Hirano et al., 2018; Nuske et al., 2019). Since services are no longer protected through IDEA following graduation and receipt of a high school diploma or through extended special education services terminating after age 21, parents must continue to advocate for their children's needs, educate potential employers on types of work accommodations, and provide informal job coaching to fill the gaps left by social services agencies (Holmes et al, 2018; McDonald, Chapter 8). Rather than stepping back to allow the young adult to grow into independence, parents and families of autistic youth find their involvement increases in complexity and intensity as they continue to play the roles of "collaborators, decision makers, and program evaluators, role models, trainers, mentors and instructors, and systems change agents" (Bianco et al., 2009, p. 186).

Studies focusing on increasing parent involvement with transition planning have focused on static variables, such as educational level and income, rather than variables amenable to change, such as parent involvement and expectations (Ruble et al., 2019). Hirano et al. (2018) remarks on the troubling lack of evidence-based interventions for increasing parent participation for transition planning for students with disabilities. Kirby's research offers affirmation that parent expectations are associated with numerous positive outcomes for autistic individuals (2016, 2020). Other research also suggests parent expectations have been associated with academic achievement and future employment though mechanism through which this occurs remains unclear (Holmes et al., 2018). Taylor and DaWalt's (2017) research suggest that maternal social support is one factor that might be associated with sustaining employment for autistic youth/adults. They raise a provocative question about the effectiveness of employment-related services and interventions for autistic individuals – are they focused on the wrong intervention target? Leaf et al (2017) cite the growing body of literature for including parent training as part of a comprehensive intervention model. They write, "parent training may result in better generalization and maintenance as individuals diagnosed with autistic can receive more hours of intervention, through parent-mediated intervention, and in settings which may lead to longer-lasting changes" (p.110). Relevant to this discussion, Taylor and DaWalt's (2017) study offers compelling evidence that families often provide supports and scaffolding needed for autistic adults to sustain employment and postsecondary education. In highlighting the integral role of these parents, Cleary et al (2023) also bring attention to the higher experience of stress, anxiety and depression, and even suicide ideation as compared to parents with typically developing children. Their findings suggest that vocational outcomes for autistic youth may be negatively influenced by parental psychological functioning and one way to increase positive adult life outcomes for students is to better support their parents.

Community-Based Supports

The Role of Vocational Rehabilitation

Vocational Rehabilitation (VR) is a federally funded program designed to help adults and youth with disabilities to achieve and maintain employment (Roux et al., 2019; Roux et al., 2021). VR is a primary point of access to community-based employment services (West et al., 1998). Employment services provided diverge along two outcomes: integrated community based or segregated/sheltered facility based (Domin & Butterworth, 2013). Sheltered employment occurs in facilities where most people have disabilities and receive training to develop work-related skills and behaviors (Armstrong, 2011) and is antithetical to the tenets of competitive integrated employment (CIE). Critics of state VR programs cite the inaccessibility and quality of services, vocational specialists and counselors with limited knowledge of autism and how to work effectively with autistic job seekers, jobs that are poorly matched between employer needs and individual interests and skills, as well as jobs that promote sheltered employment with low wages (Chen et al., 2015; Roux et al., 2019). One of the most damaging criticisms leveled against VR and its' association with sheltered employment, is its' function as a program in which people with disabilities remain for years, exploited for their labor, and without an eventual move to CIE (Armstrong, 2011).

In order to understand the criticisms leveled against VR, it is important to look at the program's history and where the intended audience changed in scope and size. VR started in 1918 to provide restorative services and retraining for World War 1 soldiers who suffered significant injuries in the war. These returning soldiers were retrained with new skills and assistance was provided to find new jobs. The program saw another expansion after 1920 to include adults with other types of disabilities, including intellectual disability. At that point, the program was still small enough to provide individualized job counseling. After 1960, the program was eventually expanded to include all adults, 16 years of age and older, who met eligibility criteria and were unable find a job. Overburdened by the influx of new cases, VR's approach to finding a job tended towards "one size fits all" and became less individualized.

Through the process of transition planning, public high schools become an important connector to many types of adult community services, including vocational rehabilitation (VR) (Anderson et al., 2021; Stevenson & Fowler, 2016). VR typically has two staff members assigned to every high school (High School students, n.d.). The role of VR staff is to help students discover their strengths and interests, career and postsecondary education options, gain work related skills and experiences, and help them create a plan to achieve their goals. VR can also have a positive impact on autistic youth/adults through promotion of communication skills directly related to job performance (Walsh et al., 2018). Learning communication and interpersonal skills are necessary in many environments, but especially in transition settings to ease the transition to work with its' different structure and expectations than school environments.

Autistic youth are a growing segment of VR users, doubling in cases every five years since 2005 (Baker-Ericzén et al., 2021). While 50-60% of autistic job-seekers find employment after using VR services, most jobs are part-time and low paying, and do not follow 'Employment First' CIE as envisioned by WIOA (Roux et al., 2019). Despite the critical importance in connecting VR's employment specialists with autistic high school students as quickly as possible, Roux and colleagues (2019) found huge disparities in VR experiences and outcomes across states in four categories: service receipt, early reach, timely development of an employment plan, and employment rate. The same research team also identified several state-level factors that influence VR services and how they impact employment outcomes for autistic youth/adults. One of those factors, staff training and competency, found that VR employment counselors are ill-equipped to manage the complex needs of autistic job-seekers. The combination of deficits related to the core characteristics of autism as well as any co-occurring mental health challenges requires ongoing access to job supports or mental health support, something that VR does not provide (Roux et al., 2019). VR also operates within the autistic medical model framework, "traditionally focused on modifying individuals' impairments versus modifying policies, practices or work environments, and have thus yielded little evidence of improvement in actual employment rates" (Roux et al., 2019, p. 285).

Despite all these challenges, emergent evidence-based practices show promise in increasing participation in competitive, integrated employment (CIE). In a review of interventions and practices that have demonstrated positive CIE outcomes, Wehman et al (2018) highlight innovative interventions such as supported and customized employment as a pathway to CIE. Other models incorporate the development of self-determination skills, person-centered planning, the use of a strengths-based approach, and the importance of parental expectations for their autistic child's potential and future as much as possible. A brief description of some of these approaches are included here:

Supported Employment

During the mid-1980s supported employment emerged in VR as an alternative to segregated, sheltered workshop employment as research demonstrated that disability populations were able to work competitively if given the opportunity and necessary supports (West et al., 1998). Supported employment is defined as "a work model that assumes that all individuals, regardless of the nature or extent of their disabilities, should have the opportunity and support to work in the community (Maybee & Swain, 2009). Wehman and colleagues describe supported employment as a "dramatic paradigm shift" (2018, p. 133) from employment in a sheltered workshop setting to one in an integrated workplace, where individuals with disabilities are viewed in terms of their contributions and not their deficits. The supported employment model eliminates emphasized on-the-job and in real time training using a "place, then train" (Wehman et al., 2018, p. 133; West et al., 1998, p. 239) rather than a "train, then place" approach" (Wehman et al., 2018, p. 133). Within the supported employment framework, the job coach assists the autistic job-seeker in finding a job, interview preparation, and providing any supports at the job itself to ensure successful employment outcomes. If there is a 'good fit' between the needs of the employer and the skills of the job-seeker, supported employment transitions into long-term support, commonly called extended supports. In a scoping review to identify effective employment interventions for autistic job-seekers, Schall et al (2020) found that CIE outcomes after participation in SE ranged from 98.4% to 100% and participants reported an 82% employment rate with all participants earning at or above minimum wage. While literature is still emerging on the promise of supported employment, thus far it shows positive outcomes (Schall et al., 2020).

Customized Employment

Created as part of the Workforce Opportunity Innovation Act (WOIA), 2014, customized employment (CE) is an extension of supported employment, and can be delivered using vocational rehabilitation funding. CE as a strategy consists of several essential elements to support the employee and employer and work towards a successful work outcome. In the CE process, an employment specialist works with the autistic job-seeker to implement CE through a well-defined discovery process that begins with an exploratory stage focusing on the individual's strengths, interests, and preferences. The discovery process is followed by the job search planning and development stage. The development stage is a unique element of CE and resembles a negotiation, with the employment specialist working collaboratively with the autistic job-seeker and potential employers to implement CE through several methods. The hallmark of a successful CE experience is employment that will match the job-seeker's interests and skills in the conditions necessary for success, and that will also fill the unmet needs of an employer. The final element in CE is post-employment support to ensure that both the individual and employer's needs are being met (Office of Disability Employment Policy, n.d.). Like the paradigm shift described in supported employment, CE is new and unfamiliar territory and requires competent and experienced employment specialists with sophisticated skills who partners with the autistic job-seeker to envision what he/she can do with the right supports and in the right environment.

Internships

Internships are paid or unpaid learning experiences that offer meaningful work and practical experience that all students with or without disabilities can benefit from and apply to future related careers. Research is clear – for autistic students, work experiences before finishing high school is one of the key indicators of employment after high school (Allison et al., 2019). Unlike supported and customized employment which outline defined components that must be followed by employment specialists, internships may be community-based, and less defined, or part of a business-led model. One national internship program, Project Search, is an immersive employment training program where students rotate between three 10–12-week internships that focus on job readiness and social skills, rather than abstract academic learning. Project SEARCH's success can be attributed to a muti-pronged model that allows for vocational exploration as well an emphasis on transferable skills, highly trained staff with instructional pedagogies that help students develop self-management and self-determination skills, and evidence-based curricula and practices to increase the likelihood of student success (Schall et al., 2020; Wehman et al., 2012). The structure provided by Project SEARCH and the length of time in each rotation also helps to build stamina and endurance for autistic youth to participate in full-time work.

The Challenge of Transition Planning for Autistic Youth

Research confirms that transition planning that actively involves both the student and the family can have a positive impact on post high-school outcomes (Hagner et al., 2014; Shogren & Plotner, 2012). On the one hand, there is considerable evidence linking effective transition practices to success in one or more life domains (employment, independent living, social relationships, postsecondary education/training). However, much of that same extant literature emphasizes the inadequacy of the transition planning process in preparing youth with disabilities, and autistic youth in particular, for successful adult futures (Shogren & Plotner, 2012). Miller-Warren (2015) found that high school transition plans "are merely pro forma and are written more for compliance rather than intention" (p. 2) suggesting that writing goals in the plan does not actually mean that implementation of those goals will actually happen. This also suggests that goals are not tied to the development of certain skills required for leading successful adult lives.

Using data from the National Longitudinal Transition Study 2 (NLTS2), Shogren and Plotner (2012) compared the transition experience for students with intellectual disability (ID), autism, and other disabilities. Their analysis revealed troubling findings. They found students with autism were significantly less likely than students with other intellectual disabilities to have goals related to competitive employment and living independently. They write,

> 39 out of every 100 students with autism …. had primary goals related to sheltered employment despite the focus on integrated employment, community participation and equal access for people with disabilities as well as data suggesting that people with disabilities earn higher wages in competitive employment. (p. 24)

Students with intellectual disability and autism also received lower progress ratings from teachers across the domains of graduation, independent living, social/interpersonal skills, and self-advocacy. They were also less likely to attend or participate in a limited manner in their IEP/Transition meetings. For post-school service needs, students with autism were the least likely to be identified as having no support needs after high school. However, students with intellectual disability *and* autism were more likely than students with other disabilities to have post-school service contacts made, suggesting that the focus on developing a greater sense of self-determination and self-advocacy in this population of ID + autistic is effective. Hatfield et al (2017) suggest one strategy of enlisting parents in helping their autistic youth see the big picture and be active participants in their transition planning process fosters the development of self-determination skills. Given the innovative options highlighted earlier that are designed to result in CIE for autistic students, there remains a critical need to explore the individual and ecological factors that predict their employment goals.

In their study examining outcomes of postsecondary education and employment for autistic youth using a national sample, Shattuck and colleagues (2012) confirmed that two normative transition periods are important for all adolescents – completing high school and pursing postsecondary education and finding employment. However, both these transition periods are fraught with increased anxiety and difficulty for autistic youth and are consistently documented through their lower rates of participation in postsecondary education and employment. Supports that are meant to bridge the transition from high school to work are largely siloed and not individualized, disenfranchising many young adults who are eager to work. Additionally, they discovered that the first two years after completion of high school are critical as autistic youth struggle to find ways to engage in other meaningful activities. Low-income youth were even more likely to be disengaged, pointing to gaps in the IEP/transition planning process.

For autistic youth, the characteristics of autism related to communication and difficulty navigating social situations are oppositional to the social experience of college (Petcu et al., 2021). In fact, Shattuck et al (2012) report that only 34.7% of autistic individuals attempt college within six years of leaving high school. The burden of entry to college and its' experience as the first foray into adulthood require a level of independence that is beyond the capacities of most autistic students. IEP plans also do not continue into college, thus, when students with disabilities leave high school, they are no longer supported under IDEA, and must be able to self-advocate and self-disclose their disability to receive reasonable accommodations (Madaus et al., 2022).

After high school, the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act help to ensure equal access and non-discrimination. Employers with 15 or more employees operate under Title 1 of the ADA which describes reasonable accommodations as a modification or adjustment to a job, the work environment, or the way things are usually done during the hiring process. These modifications enable an individual with a disability to have an equal opportunity not only to get a job, but successfully perform their job tasks to the same extent as people without disabilities" (U.S. Department of Labor, n.d.). However, schools and employers require disclosure of the disability and documentation evidencing the need for supports or accommodations. This creates a need for students and autistic youth/adults to understand, communicate, and advocate for their needs, something they may not have been responsible for in the past. Compounding this challenge are employers who may not understand the types of accommodations that can be provided and are thus hesitant about hiring disabled workers (Stone, 2022). University disability offices are also rarely equipped to provide the types of supports that would make the college experience successful for autistic students (Petcu et al., 2021).

Taylor and DaWalt's (2017) study confirm that the period after high school is considerably unstable for young adults, "with the average youth having seven jobs between the ages of 18 and 28" (p. 4031). While frequent job changes might be a common occurrence with typically developing youth, they state the frequency of job transitions for autistic youth are likely a reflection of poor fit or lack of appropriate supports. They also suggest that repeated disruptions during the critical years after high school exit set the stage for chronic unemployment or underemployment throughout adulthood, underscoring the importance of timely and tailored support during transition planning for autistic youth.

In another study, Taylor and Seltzer (2011) highlighted the lack of literature examining how the characteristics of autistic individuals predict their post-high school occupational and employment activities. Their study posits that some autistic youth without intellectual disability (ID) are at risk for poor employment outcomes in adulthood due to an increase in repetitive and maladaptive behaviors. Taylor and Seltzer (2017) study found that change in symptoms and maladaptive behaviors after high school exit was worse for low-income youths without ID, possibly due to the lack of structured activities. In their study sample, only 18% of young adults without ID received some sort of employment or vocational services compared to 86% of young adults with ID, suggesting that current developmental disability service system does not appear to be accommodating the unique needs of autistic job-seekers without ID. An important finding their study highlights is that there is subset of autistic youth without ID who are at greater risk of “falling through the cracks” during the transition to adulthood. Falling through the cracks refers to students without ID assumed to require fewer supports in order to achieve successful adult outcomes, as compared to students with ID.

HRD and Employment for Neurodivergent Populations

Human Resource Development (HRD) is a collaborative discipline that draws from psychological theory, systems theory, and economic theory (Swanson, 1995). It has been defined as “a process of developing and/or unleashing human expertise through organization development and personnel training and development for the purpose of improving performance” (Swanson, 1995, p. 208). McLean and McLean’s global definition of HRD appeals to HRD’s humanistic tradition and is more aligned with the purposes of this dissertation. They write, “Human resource development is any process or activity that, either initially or over the long term, has the potential to develop adults’ work-based knowledge, expertise, productivity, and satisfaction, whether for personal or group/team gain, or for the benefit of an organization, community, nation or, ultimately, the whole of humanity” (2001, p. 322).

The World Health Organization estimates that around the world ~785 million people with disabilities are of working age, 16-64 (Procknow & Rocco, 2016). In the United States, the unemployment rate for persons aged 16-64 with a disability is 10.8%, twice that of the population of the same age range without a disability (U.S. Department of Labor, 2021). Procknow and Rocco (2016) argue that adults with disabilities remain an underutilized segment of the working labor pool. One possible explanation for low employment rates in autistic populations is the movement to a knowledge-based economy, employees with more secondary training, and jobs that require the ability to successfully interact and communicate with others – elements that are difficult for autistic employees to achieve and maintain (Roux et al., 2019). Despite the humanistic and developmental aim of the discipline, HRD has not been successful in advocating the equal opportunities of people with disabilities and supporting their full integration at work (Kwon, 2020).

The literature in previous sections highlights the lack of preparation received through special education and vocational rehabilitation in preparing autistic youth for future employment. The current landscape of employment for autistic youth/adults is dismal, with unemployment rates >85% (Roux et al., 2015). Research has documented that autistic people want to work, as they recognize that employment is important at an individual level and provides income which is used to achieve independence (Bush & Tassé, 2017). Employment is important at a societal level and reduces the need for governmental support (Hurley-Hanson et al., 2020). For autistic youth/adults, employment improves quality of life as well as increased cognitive functioning, improved social interaction opportunities, development of peer relationships, and reduced anxiety and depression (Walsh et al., 2017).

Autistic people bring strengths to the workplace including attention to detail, logical reasoning, honesty, passionate interests and loyalty (Remington et al., 2022). Cope and Remington's (2021) study investigated self-reported strengths of 66 autistic participants to promote bolster awareness in autistic populations themselves, and highlight these strengths to other researchers and employers in their efforts to recruit, train, and retain autistic employees. Their study confirmed previous findings of areas of strength related to cognitive advantages and efficiency, but also revealed other unique strengths, such as a strong sense of social justice and fairness, and creative and diverse perspectives.

The literature review presented earlier highlighted the lack of social skills development related to the attainment of successful adult outcomes, one of which is employment. Once employed, other frequently reported obstacles for autistic employees include difficulties around interpersonal communication, relationship management, learning and applying knowledge, task management and mental health management, which align with the social and cognitive challenges associated with being autistic (Bush & Tassé, 2017). Support from the business community is minimal at best and largely dependent on business size, with the greatest participation from bigger organizations with resources and personnel to support these efforts. Roux et al (2019) have commented on the role of employers and employment development professionals in reducing barriers to employment for people with disabilities. They add that special attention needs to be given to the employment support needs of autistic populations given the social-cognitive, behavioral, and communication impairments associated with autism, as well as any co-occurring mental health challenges. There is a pressing need for greater research that focuses on both adults with disabilities' individual characteristics associated with employability (Bush & Tassé, 2017), and reducing bias and stigma with employers and in workplaces.

Theoretical Framework

Heng (2020) and Collins and Stockton (2018) offer a useful description of a theoretical framework. A theory is "is a big idea that organizes many other ideas". The use of a theoretical framework in a study organizes one or more theories to map relationships between ideas and "provides a clearly articulated signpost or lens for how the study will process new knowledge"

(Collins & Stockton, 2018, p. 2). In this study, two different theories were used: expectancy value theory and broaden-and-build theory. Expectancy value theory (Wigfield & Eccles, 2000) is useful in understanding how parent expectations impact their autistic child's future outcomes. Broaden-and-build theory (Fredrickson, 2001), as part the positive psychology paradigm, helps expand the role of positive parent expectations to understand how achievement of expectations leads to larger gains in their children's abilities and attaining outcomes such as CIE. Both theories offer a positive and strength-based perspective to understand how parents of autistic children navigate and overcome the largely deficit-based approaches that typify care for autistic populations.

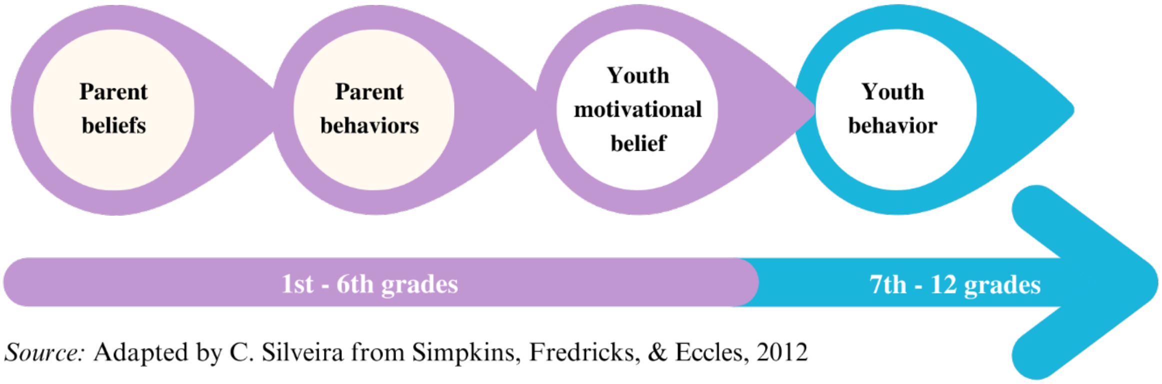
Expectancy-Value Theory

Expectancy-value (E-V) theory is a motivational theory developed by Eccles and Wigfield and was originally used as a framework to study youth performance and choice in the mathematics achievement domain (Wigfield & Eccles, 2000) and defined expectancies as a youth's belief about how well they will perform on an immediate task or a task in the long-term future. The study authors posit that "individuals choice, persistence, and performance can be explained by their beliefs about how well they will do on the activity and the extent to which they value the activity" (p. 25).

Using an expanded E-V model, Simpkins et al (2012) adapted it to describe the process by which parents' beliefs about their elementary children are later associated with their children's achievement-related behaviors during adolescence. Four domains were examined in this study: sports, music, math, and reading. In their three-step process, as shown in Figure 2, Simpkins and colleagues proposed that parental beliefs in a domain especially in early elementary years, shape their behavior towards engaging their child(ren) in that domain. In later elementary and middle school years, parents' behaviors in turn influence youth' motivational beliefs with these beliefs predicting children's subsequent behaviors.

Figure 2

Eccles' Expectancy Value Theory



Source: Adapted by C. Silveira from Simpkins, Fredricks, & Eccles, 2012

Doren, Gau, and Lindstrom (2012) explored how the expectations of parents of children with disabilities, regarding their adolescent's beliefs, values, and abilities impacted future outcomes. Their research suggests that parent expectations were "significantly and powerfully associated" with several outcomes, including graduating from high school with a standard diploma, attending post-secondary education, and obtaining a job (p. 19). In their study of mothers with Down Syndrome young adult children, Docherty and Reid (2009) suggest that parent attitudes, values, and expectations sustain the parent-child relationship. Applying E-V theory to autistic populations, Kirby found that parental expectations were a mediating factor in their autistic child(ren)'s future outcomes related to postsecondary education, independent living, and employment.

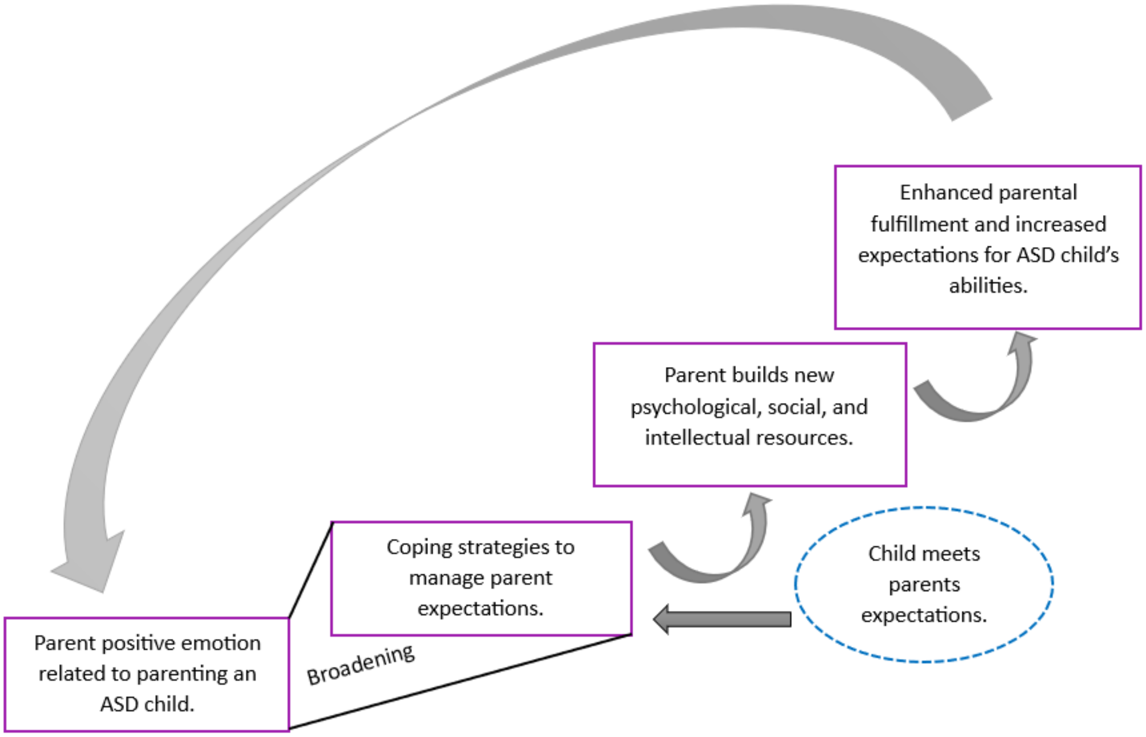
Broaden-and-Build Theory

Barbara Fredrickson’s broaden-and-build theory (2001) offers a unique perspective to consider how positive parent emotions play a role in affecting their autistic children’s outcomes. In her seminal paper, she posits that “experiences of positive emotions broaden people's momentary thought-action repertoires, which in turn serves to build their enduring personal resources, ranging from physical and intellectual resources to social and psychological resources” (Fredrickson, 2001, p. 218). Fredrickson acknowledges the co-existence of positive and negative emotions and contends that they play dynamic, but different roles in stressful situations. She states the experience of positive emotions has a dual thought and action response (what Fredrickson terms, ‘momentary thought-action repertoires’) that is significant in strengthening and building upon a person’s resources. In the context of facing challenges, Fredrickson posits that negative emotions limit attentional span, but positive emotions have the dual role of broadening the scope of thinking, and building/widening the boundaries of problem solving. Thus, the experience of broadening and building results in a higher ratio of positive emotion, quells negative emotion, and adds to an upward spiral towards strengthened resiliency to cope with stressors (Fredrickson, 2001; Trute et al., 2011).

Consider the following: parenting a disabled child is often associated with parental distress (Trute et al., 2011). Similarly, parenting a neurodiverse child can be physically, emotionally, and mentally challenging; however, research has found that parents often respond to these challenges through the process of stress-related growth that builds resiliency (Trute et al., 2011). Trute (2011) suggests that through the process of stress-related growth, parents modify or create positive coping strategies to manage their own expectations. Positive goal achievement by their child can inspire parent's positive emotions, including pride, joy, and love, and can broaden parent's "momentary thought-action repertoires, widening the array of the thoughts and actions" (p. 220). The widening of parents' positive thoughts and actions also affects future expectations.

Figure 3

Broaden-and-build theory applied to parent expectations of their autistic child.



Source: Adapted by C. Silveira from Fredrickson & Cohn, 2008

Figure 3 (above) represents an adaptation of Barbara Fredrickson's broaden-and-build model (Fredrickson & Cohn, 2008) applied to parent expectations of their autistic child's capabilities. The broaden-and-build theory is situated in the positive psychology paradigm, thus it is helpful to envision the entry to this model as a parent's positive perspective to parenting an autistic child.

Fredrickson’s theory has implications for both parents and their autistic children related to the achievement of adult outcomes. In the case of their autistic child, pride in their children’s achievements broadens parent’s positive emotions by “creating the urge to share the news and to envision even greater achievements [*for their child*] in the future” (p. 220). Envisioning greater future achievements becomes aligned with new parent expectations which require parents to build their own social, intellectual, and psychological resources, and seek out new activities for their child. Iterative cycles related to achieving increased expectations create an upward spiral that promotes discovery and produces more positive emotion. The expansion of broaden-and-build theory applied to the role of positive parent expectations is helpful in understanding how achievement of parent expectations leads to larger gains in their children’s abilities and attaining outcomes such as CIE. Expectancy value theory and Fredrickson’s research fit within the positive psychology framework which considers the role of social and behavioral sciences in developing well-being and flourishing communities (Fredrickson, 2001; Seligman & Csikszentmihalyi, 2000).

Summary

This study examined the experiences of parents of autistic young adults who have helped their children navigate post-school transition to attain competitive, integrated employment. Parents continue to be the main source of supports for their autistic children, thus the literature in this review explores the role of parents in greater detail. Two theories that support the role of parents in creating successful outcomes for their autistic child are Wigfield and Eccles’ (2000) expectancy value theory and Fredrickson’s (2001) broaden-and-build theory.

An introduction to autism and its' categorization as a disability was presented along with differences between the medical and social models of disability. Background to educational disability laws and policy was shared; findings indicated that comprehensive transition services provided by schools may be insufficient preparation to achieve the most common adult outcomes of independence, CIE, and social connectivity. Employment data for autistic populations continues to hover at an ~85% unemployment rate so understanding other supports besides parents that can positively impact employment remains vital. Here too, findings reveal that the services provided by adult social services, such as Vocational Rehabilitation are insufficient and not tailored to meet the needs of autistic populations.

Chapter Three

Methodology

In this chapter, I discuss the qualitative study methodology and design, and why this was the best approach for my study. I explain how my experiences as the parent of an autistic child have contributed to my understanding of autism and how these experiences inform my own strategies which contribute to obtaining competitive, integrative employment. I detail my data collection tools, including the participant selection and criteria, data collection methods, and the qualitative data analysis process used. Lastly, Chapter Three will address qualitative study considerations of trustworthiness, demonstrated through the criteria of credibility, transferability, and dependability of the study.

The purpose of this qualitative case study was to explore in rich detail, how parents of autistic young adults have helped them navigate a post-school transition into adulthood and obtain CIE. Parents are their autistic child's strongest advocate, but also understand their child's strengths and challenges relative to achieving successful adult outcomes, especially those related to employment. The variability of autism as a spectrum condition as well as any co-occurring intellectual disability and psychiatric disorders, all play a contributing role in defining what success looks like for each person. Thus, successful adult outcomes too, are subjective and variable. Through this process, I sought to explore parents' expectations for the future, resources and strategies they used, their experience navigating the transition process, and other supports that were valuable in helping their children build work-related skills and find meaningful employment. The following research question guided this study:

How do parents of autistic children help them navigate a post-school transition and obtain competitive, integrated employment?

Several additional questions related to the study's primary question include:

a. In what ways do expectations of parents inform the experience of their autistic child(ren) obtaining post-high school competitive, integrated employment?
b. What role did schools play in supporting the transition to postschool employment?
c. What IEP/transition goals aligned with achieving competitive, integrated employment?
d. What challenges do parents report experiencing in helping their child achieve integrated competitive employment?
e. What types of formal (community service agency) and informal (friend, family) support did parents perceive as most essential to their child's success?

In this study, I define competitive, integrated employment as part-time or full-time work where the autistic individual is paid similarly to other employees without disabilities doing the same work, in the same work environment as other individuals without disabilities, and where they have opportunities for advancement like other employees without disabilities (Competitive Integrated Employment, n.d.). Likewise, success is subjective, and is partially defined by the expectations of parents, abilities of their children and any co-occurring psychiatric conditions, and employments that fits their interests and strengths. My goal with this research study is to add to the understanding of services and supports that are available to assist autistic youth in transition planning. My greatest hope is that the learnings from this study can elevate efforts in promoting employment for other autistic adults.

Finally, I hope to add to the literature on transition planning for autistic adults and raise awareness on this important topic with several audiences which include, other parents with autistic children, special education teachers, vocational rehabilitation counselors, researchers, policymakers, and with employers on the strengths of a neurodivergent workforce. I am invested in supporting all parents, but especially those with limited access to therapies and resources to become better advocates for their children as they start to age through the special education system and approach transition planning. Through this process, I emphasize the need for and importance of appropriate and timely support to ensure the overall wellbeing of the entire family.

Insider Research: A Place for Acceptance

"Making the decision to have a child - it is momentous. It is to decide forever to have your heart go walking around outside your body."

Elizabeth Stone

Qualitative research designs are heavily informed by the researcher. This qualitative research approach uses the researcher as the primary data collection instrument (Cypress, 2017) and requires them to understand their own positionality and remain critically reflexive (Sutton & Austin, 2015). Sutton and Austin (2015) further caution that even researchers are not able to ignore their own biases. Instead, they encourage the use of reflexivity which "requires researchers to reflect upon and clearly articulate their position and subjectivities" (p. 226).

It is important to share my story, my lived experience because it is foundational to this study and my beliefs and values around activism and advocacy. These experiences provided me with several reflexive perspectives from which to answer the questions I wanted to address in my doctoral work. I am an Asian-Indian female who was born in Bombay, India but grew up in

Dubai, United Arab Emirates. I graduated from high school at fifteen, completed one year of undergraduate courses at an American college in Dubai, then transferred to a state university in Minnesota in 1995 to finish my bachelor's degree. I met my husband two years into my undergraduate work and married in 1998. Four children later, we divorced in 2011.

I solo-parented my way through graduate school. During that process, I started interning with a Native American non-profit in South Minneapolis. That internship led to paid employment after I graduated with a dual master's degree in public health nutrition and dietetics. I worked as a community dietitian with an urban Native American population which gave me the opportunity to develop advocacy skills and learn how to tailor programs for audiences that have experienced generational trauma. While I enjoyed the work, I wanted to expand my skills and knowledge of working with different audiences. In late 2014, I accepted a job as an Extension Educator, coordinating state operations for a federal nutrition education program delivered through Land Grant Universities. It was in this role that I continue to hone my advocacy and systems-navigation skills, supporting nutrition educators to deliver programs in communities that reflected their cultural backgrounds of Hmong, Karen, Latino, Native American, as well as historical Black populations. Working with these two organizations afforded me the opportunity to understand the importance of individualized education and the resilience of families and communities that have seen continued disinvestment.

I also know that my perspectives as a parent have shaped the type of work to which I am drawn. I have four children aged 23 to 16. I helped my eldest daughter apply to, navigate financial aid, and graduate from university with a four-year degree with minimal debt. She is working in her discipline area and preparing for graduate school next Fall. My third child is a

Senior in college and will graduate next year. My youngest daughter is in 11th grade in high school and is also taking post-secondary education classes at a nearby university. As a parent, I consider these experiences successful and aligned with my expectations of them as well as developmental milestones for typically developing children.

It is my experiences as a parent of an autistic child, however, that have contributed the most to my identity as an advocate. My second child, Zachariah is autistic, and was diagnosed at an early age. I never thought I would need to advocate within my family for Zachariah to need therapy. My ex-husband who is Black, refused to believe his son had a disability, and at first, prevented me from seeking any services. Mental health and disability are taboo topics in many cultural communities including Black communities. Instead of therapy, he told me that I needed to be a better parent. When early childhood family education came out for the initial evaluation, I remember scheduling it when their dad was not home. Finally when someone at the prayer center he attended revealed that their son too had a developmental delay, he stopped arguing with me when I would take Zachariah to therapy.

Zachariah has a primary diagnosis of autistic, with secondary diagnoses of attention deficit hyperactivity disorder (ADHD), as well as depression and anxiety. As a young child, he also had a charming smile, two huge dimples, and a tendency to run off and explore whenever he was put down. I still remember with fright an incident that occurred when he was about two years old. The children and I were visiting my parents in Toronto, and my mother and I decided to take them to a splashpad that bordered Lake Ontario. I remember setting Zachariah down, turning around to pick up my other crying child, turning back around and Zachariah was nowhere to be found. After an hour of searching, checking the lake to make sure he hadn’t fallen in, and calling the park police, we found him playing happily in the sand. What I remember most during that time was telling the park police that he was completely nonverbal and would not respond to his name. Going to the grocery store, an amusement park, or to a shopping mall was always difficult. When he was younger, he would throw himself on the floor, cover his ears, and scream. I still remember the looks from other parents; I interpreted those as judgement about my child's "bad" behavior, and condemnation regarding my inability to control my child. Finally, even those outings stopped. These are just a few incidents of many I experienced raising an autistic child and thought several times of how he or I would cope as he became older.

To this day, Zachariah continues to need therapies to support his dysregulated sensory processing. Because he was nonverbal for so long, I started first with speech therapy. The therapy center we attended offered me both speech and occupational therapy (OT). I accepted, not really understanding what OT was. I clearly remember pursuing a stage of intense research about autism and potential cures till my son was about ten years old. The research stage abruptly stopped when I became overwhelmed with information, and none led to a cure. Since that time and up to about four years ago, I can say that while I would read articles occasionally, I fell into maintenance stage that was the result of solo parenting, attending graduate school, and managing therapies for Zachariah. That deep research stage however, led to therapies such as music therapy, tutoring to bolster his math and reading skills, craniosacral massage, more speech and OT, week-long summer camps that immersed him in all types of sensory therapies, adaptive bike camps, talk therapy and social skills groups, technology camps for children with autism, and so on. This is not an exhaustive list, but it represents my ability to throw whatever I could at the situation to help increase his executive functioning skills and find areas that he could excel in.

When Zachariah received a medical diagnosis of autism, it finally gave me permission to advocate for special education services for him. At the elementary, middle, and high school levels, testing and evaluation was administered to help inform his IEP goals. In middle school, one of his tests revealed an IQ of 127. Since Zachariah received state-funded services, including health insurance, this information was sent to the county to be included as part of his ongoing care. A few weeks later I received a letter from his case manager informing me that his case was being closed as his IQ was too high and he did not qualify for services. It took a year of arguing with the county as well as an appeal to ensure my son's care and services were reinstated. My appeal to the judge was simple – my son might be able to take apart a computer and put it back together, but he cannot cross the street without help. Elevated functioning in one area does not indicate proficiency in all areas of their life, and not all autistic people have intellectual disabilities.

After each school-age transition that Zachariah had, I kept waiting for him to be different, to communicate better, to answer questions without multiple prompts, to be more flexible regarding his routine – to be more independent. At each transition period, elementary school to middle school, middle school to high school, not seeing the type of progress I wanted to, renewed my cycle of grieving. Parents of autistic children experience cyclical grief aligning with the Kübler-Ross model at various points throughout their lifespan: shock and denial, anger, resentment and guilt, bargaining, depression, and adjustment/acceptance (Rabba et al., 2019). Although the original development of the Kübler-Ross stages of grief was in the context of someone dealing with illness or death, the model has been adapted to be applicable to people experiencing any form of grief or loss.

The next few several years of his high school experience are somewhat blurry. I remember moving from middle school to high school IEPs and still distinctly remember his first high school IEP. To my surprise, it was written in…. plain language! It contained little to no jargon, was relatively short, and contained definitive goals I could understand and support at home. I never knew that an IEP could be so simple. Zachariah's special education teacher and case manager introduced me via email to vocational rehabilitation services (VRS) when he was in ninth grade. The VRS counselor was amazing and was very supportive of any education I wanted to pursue for him. However, none of the IEP/Transition team had any suggestions on where I could find specialized education or programming for him.

In reflecting on those transition periods, I realized what I was waiting for was for him to be cured – to suddenly stop being autistic. Finally, after high school and in early 2020 when the COVID-19 pandemic hit, all the services that supported him came to an abrupt halt. Zachariah was home 24/7. Every intervention that provided support for him (and respite for me) stopped. It was at this time that I truly understood that this would be a lifelong condition for him, but also for me. It was also around that same time that I was preparing for my doctoral oral exams, and I briefly entertained the idea of switching my thesis topic at that time for the one I am doing now, but just as quickly dismissed it. It was hard enough living with a child with neurodiverse needs every day, I did not need to go study more about it. I needed separation, or so I thought. Zachariah was also approaching the cut-off age to receive IDEA-related education and services and I needed to find adult services that would support him in his next stage of life.

To prepare Zachariah for life after high school, I started looking into programs that would help him live a fulfilled, meaningful, and independent as possible life. My search began when he entered middle school and when he started telling me that he wanted to do similar things as his typically developing siblings. I identified programmatic resources through a website called ThinkCollege.net, a clearinghouse of resources focusing on post-secondary education options for people with disabilities. Many of these programs combine living and career skills development, but do not culminate in any sort of certificate or degree recognized outside the program. There are also a limited number of higher education institutions that provide a specialized program for young adults on the spectrum. While there is burgeoning literature on the accommodations provided by universities and colleges, at the time I was looking, I could not find programs that had a blended academic and life skills program. I also knew that for my son and other students like him with similar support needs, challenges associated with social situations makes college an impossibility. This meant obtaining employable work skills are critical in their road to independence. I came to yet another realization: if there was not a program that already existed and fit his needs, I would need to put one together.

By then I had started working at the University of Minnesota. I knew I needed to have options for him after high school and went back to the ThinkCollege.net website. One of the resources led me to the Institute for Community Integration and a meeting with Dr. David Johnson, its' director at the time. While I don't remember the entirety of our conversation, I distinctly remember one thing he shared with me. Dr. Johnson affirmed the work I had been doing to support my son *and* acknowledged that what I was looking for Zachariah did not exist; i.e., there would always be a need to curate and create resources for him. I also reached out to an organization called MindShift which harnesses the "detail-oriented skills of people on the autism spectrum while providing meaningful, sustainable employment" (About MindShift, 2022). Their director emphasized that if college was not an option for my son, and if his interest was technology, he should obtain as many certifications as possible to make him a competitive candidate.

With these two recommendations in mind, the summer Zachariah turned 16, I applied on his behalf for a youth employment program called Step-Up! run by the City of Minneapolis. Through this program, Zachariah worked a series of summer jobs from 2016 to 2021, apart from 2020 during the COVID-19 pandemic. At that time, I was not aware of the literature supporting the need for autistic youth to have paid employment before completion of high school. I only knew that 18, and then the dreaded 21 cliff was soon approaching, and my expectations for his future included competitive, integrated employment. That meant narrowing in on his interests, and matching those as closely as possible with work experiences so that he could become familiar with the necessary skills, and the process of working.

Before Zachariah turned 18, I also needed to apply for legal guardianship, as well as Social Security Disability Benefits. The county provided me with a list of lawyers, but it was up to me to call each of them and see if they would be willing to take our case. If I did not receive guardianship before he turned 18, I could not continue to make decisions for him as he was legally an adult regardless of personal capacity, and responsibility for his care would be taken over by the state. In hindsight, the legal process was relatively easy, but the process to receive social security benefits was arduous and demoralizing. The county assigned us a special case worker to help manage the many forms and tests that Zachariah needed to undergo. Even with his help, our first attempt was denied. The county case worker was not fazed. He simply shared that everyone’s first attempts were denied and only if you applied again, you would be approved the second time. I was furious; I knew without my help and without the county worker, Zachariah would never be able to get through the process, let alone know there *was* a process.

Then, in late 2020, I applied for, and received a Fellowship from the Carlson School of Business Management at the University of Minnesota to explore any topic related to disparities in education. I chose to explore what comes after the cliff – age 21 – for autistic individuals. The work was both exhilarating and terrifying. It was the first time I was able to see how my personal experience and my academic work could align and bring hope and new possibilities for my son and other young adults who had similar support needs. I also reconnected with MindShift who now had a new director, Joy Kieffer. Joy and I are now close, partnering together on other grants and projects that seek to increase the CIE opportunities for autistic populations. The gift of time afforded by the fellowship helped me to connect with programs and organizations around the country, and even in Toronto, Canada and Brisbane, Australia. I learned that while there are legislative differences in other states and countries, the community doing this work is eager to share information. When the Carlson fellowship ended in December 2021, a second shorter fellowship between MN Lend and the University of Minnesota, Extension in January 2022 provided a seamless transition to allow me to continue doing this work.

It has been more than 47 years since the first Education act for Handicapped children (EHA) was passed. The first wave of students who received mandated special education and services under that act are now adults. Transition outcomes related to employment for autistic populations still lag those with other disabilities. My goal with both those fellowships and my doctoral work is to share parts of my experiences as the parent of an autistic child, as well as listen to, and share the experiences of parents who have successfully transitioned their autistic child into CIE. A second goal of mine relates to being part of a growing social and political consciousness around (dis)ability populations, who gets to participate in the world of work, and help develop meaningful accommodations to make work a reality for autistic populations (Zahavi, 2020). My doctoral studies have helped me develop a solid grounding in research-related skills in order to address my second goal. Foundational research classes in qualitative and quantitative methodologies helped me shift my paradigm from everyday practical applications related to education and training, to the theoretical and analytical work of research. I would urge other doctoral students to take the time to explore both methodologies and find meaningful research projects to make the connection between course content and application to real problems.

Research Design

This study aspired to give voice to the complex lives of parents of autistic children by asking the question: How do parents of autistic children help them navigate a post-school transition into adulthood and obtain competitive, integrated employment? Autism is a heterogenous condition; thus, no two people are alike and strategies and supports for each person must be tailored for their needs. Although I was interested in understanding the role that special education and transitions programs play in helping young people prepare for entry into the labor market, these programs are just one piece of the larger journey to navigate CIE, with parents playing a critical role in their success. Autism's heterogenous condition also means that success is subjective and is partially defined by the expectations of parents, abilities of their children and any co-occurring psychiatric conditions, and employments that fits their interests and strengths. For many families, while schools play an important role in the IEP/transition planning process, the burden of coordination of services both before and after high school fall to the parent. Furthermore, autistic characteristics which often include social and communication challenges, require ongoing parental engagement, support, and advocacy on their behalf to succeed in the adult domains of employment, social connectivity, and independent living. As a parent on a similar journey, the motivation behind this study was to center and elevate the successes and struggles of parents, and highlight strategies that have been successful in supporting their children in obtaining CIE. To understand the complexity of these experiences, I used a qualitative study design with a multiple case study approach.

Khan (2014) states that qualitative research can be located in positivist, interpretivist, and critical paradigms. Qualitative research design was appropriate for this study because it is interpretive, fit the nature of the research questions, and allowed me to explore experiences from different parents, which provided opportunities for comparisons and descriptions of similar and unique phenomena (Yin, 2013). In choosing case study as a method, I echo Bartlett and Vavrus' (2017) insight in selecting and conceptualizing case studies as depending on "the epistemology and methodology engaged by the author" (p. 27). My experiences as a parent, HRD student, immigrant, and advocate all contributed to how I approached this study, as did my awareness of neurodiversity which acknowledges autism as a way of being and not a disability (Sinclair, 1993). These perspectives together with appropriate theories provided a deeper understanding of the processes leading to positive employment outcomes in autistic youth/adults.

Case Study

Case study research is located within the qualitative paradigm and can used to systematically study a phenomenon "when the variables are …. too embedded in the phenomenon to be extracted for study" (Merriam, 1998, p. 7). It also assumes that examining the context and other complexities related to the case as being integral to the case (Zucker, 2009). Case studies serve to answer questions that the researcher does not have much control over the phenomenon studied. Use of this research methodology can be exploratory, explanatory, or descriptive in nature and is valuable for generating an in-depth understanding of the world around us or explaining why a particular event or situation occurred. According to Merriam (1998), "a descriptive case study….is one that presents a detailed account of the phenomenon under study…. that chronicles a sequence of events" (p. 27).

Case study methodology is a common approach used in multiple disciplines and fields (Bartlett & Vavrus, 2016) and is recommended when the goal of the study is to understand how or why something occurs (Merriam, 1998; Yin, 2003). Three prominent researchers, Robert Yin, Robert Stake, and Sharan Merriam have defined and outlined methods for case study research. This study has been influenced by the work of Merriam (1998) and Stake (1995), who frequently establish their epistemic stance of case study in constructivist/interpretative approaches and as a qualitative methodology (Mishra, 2021). Merriam offers a definition of case study as "an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit" (Merriam, 1998, p. 16). Conversely, Stake (1995) offers no formal definition of case study, but proposes that "the case is a specific, a complex, functioning thing" and "the case is an integrated system" (p. 2). Yin (2017) adds that the case study is a research strategy that comprises a method that encompasses specific approaches to data collection and analysis.

According to Merriam, defining characteristics of a case study are:

a) Particularistic (focusing on a particular situation, event, program, or phenomenon)

b) Descriptive (yielding a rich, thick description of the phenomenon under study), and

c) Heuristic (illuminating the reader's understanding of phenomenon under study).

Stake (1995) distinguishes between three types of cases: *intrinsic, instrumental,* and *collective*. Intrinsic cases are undertaken when the researcher wants to know more about that particular case – understanding the case is not a prelude to understanding something else. On the other hand, instrumental cases are used when the researcher uses one case in order to understand something that is happening as a part of a larger phenomenon. Finally, collective case study follows similar thinking as with instrumental cases, but instead of a single case, the researcher may use a collection of cases.

As part of the qualitative tradition, case studies can consist of a single case with carefully chosen methods employed to deepen understanding of that individual unit (Bartlett & Vavrus, 2017; Yazan, 2015). In collective or multiple case studies, a number of carefully selected cases can offer an opportunity to study multiple cases simultaneously to allow for comparisons across cases and generate a broader understanding of a particular phenomenon (Crowe et al., 2011). This qualitative research project used a collective case study approach to describe how parents of autistic children helped them transition from post-school into adulthood and obtain CIE. After the phenomenon of interest has been identified, the unit of analysis can be defined. Merriam (1998) defines the unit of analysis as "an individual, a program, an institution, a group, an event, a concept" (p. 45). The research proposed here identifies a case as the rich description of the processes and events that lead to CIE for autistic young adults and the unit of analysis as the parent voice that is narrating their story. Parent voice was selected as the unit of analysis, as outside of the autistic individual themselves, they are likely the people who know and understand their child best.

As pointed out earlier, parents have often been referred to as the “linchpins” of services for their autistic children (Burke et al., 2019, p. 514). Thus, understanding how parents navigate, on behalf of their child, systems of education, social services systems, and other supports that impact the development and future success of their autistic child is a critical problem of practice both from an educational and societal perspective. By gaining insight into how some families have navigated this phenomenon, it can have a lasting impact for future families who will inevitably experience similar challenges in helping their autistic child obtain employment.

Due to the complexity of autism and the problem proposed in this study, case study was the right choice because of the descriptive nature of the research question, the rich description and thoughtful answers offered by parents during interviews that I sought to include in themes and interpretation, and the emphasis on the study of the phenomenon within its’ real-world context. Merriam views research that focuses on establishing “insight, discovery, and interpretation rather than hypothesis testing” for critical problems of practice as being aligned with case study design (1998, p. 10).

As a qualitative approach, this study must also contend with reliability of the interpretation and representation of participants’ narratives (Sutton & Austin, 2015). Citing the influential work of Lincoln and Guba, this is referred to as “trustworthiness” in qualitative research and contains four criteria: “transferability (showing that the finding have applicability in other contexts), dependability (showing that findings are consistent and could be repeated), credibility (confidence in the truth of the findings), and confirmability (the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest)” (Sutton & Austin, 2015, p. 229).

One of the frequent criticisms of case study research is that the results are not widely applicable, or generalizable in real life (Tellis, 1997). Merriam (1998) suggests three processes to improve the generalizability of findings – providing rich, thick description, establishing how typical the case is in comparison with others in similar situations or through cross-case analysis. Cross-case analysis is described further in the data analysis section. In this study, while generalization to broader audiences is not the goal, there are important lessons for special education staff, workforce development staff, and HRD researchers and practitioners to be learned from the narratives of parents.

Another central aspect to qualitative research and related to sample size is saturation. Several scholars have discussed the topic of saturation as it relates to qualitative research and sampling (Saldaña, 2013; Sandelowski, 1995; Saunders et al, 2018) with most describing it as the point where additional data collection and analyses does not contribute any new data to the study (Gentles et al., 2015). Yin (2013) offers that the curated selection of cases for case study research and its’ focus on in-depth and contextual nuances often mean that a well-done study will likely only be able to include a small number of cases.

Methods

Using a qualitative case study design, this study engaged five parents of autistic young adults in semi-structured interviews to explore how they helped their children navigate a post-school path to transition into adulthood and obtain CIE. My data sources comprised of transcripts from interviews, observations of parents during interviews, and an in-depth literature review to study the phenomenon of interest. In the findings section, participants' own language with direct quotation used as much as possible in an effort to retain the integrity of stories and meanings.

For this study, I interviewed five parents of autistic young adults. While my intent was to meet and speak with each parent face-to-face, I was only able to schedule two interviews in-person. The remaining three occurred virtually via a Zoom platform due to parents' schedules and geographic location. Out of the five parents I interviewed, three were married, and the other two were divorced and remarried. All five were parents of one or more children formally diagnosed with autism, their children were currently employed, or had been employed in a competitive, integrated job. All five young adults had an IEP in school and had some experience with IEP/transition planning.

While five parents represent a small sample size, this size is characteristic of qualitative approaches to sampling and represents an important distinction from quantitative research which often utilizes larger sample sizes and statistical precision. Qualitative research is often concerned with obtaining information that provides a rich and deep understanding of the depth, complexity, variation, and context as it concerns a certain phenomenon. Consequently, smaller sample sizes are often used in qualitative research (Gentles et al., 2015).

Researcher Bias

In context, I often see the world and accommodations through the lens of what my son needs to participate as fully as he can in the world. Consequently, I have engaged him in many successful (and not-so-successful) therapies over the years, have met many other parents on similar journeys, and have a broad network to draw from. Reflexivity will be a practice I use throughout this study because of my connection to, and vested interest in the study. Cypress

(2017) describes the process of reflexivity for researchers as the ability to "actively engage in critical self-reflection about their potential biases and predispositions that they bring to the qualitative study" (p. 259). Researcher reflexivity also contextualizes the work for other researchers and forms the filer through which the data will be examined (Sutton & Austin, 2015).

Ethics Consideration

My first step was to apply for human subjects' research approval. I applied to the University of Minnesota's Institutional Review Board (IRB) on January 10, 2023, and received approval on January 27th.

Participant Selection, Inclusion Criteria, and Confidentiality

To ensure that I engaged in conversations with parents whose autistic children had already gone through the transition process, I used purposive sampling. Purposive sampling is a common sampling method to use when the selection of a specific group of participants can better inform the researcher regarding a particular issue (Khan, 2014). As this study focused specifically on parents of autistic young adults who helped them navigate post-school transition and obtain CIE, purposive sampling was the most appropriate method to recruit participants for the study (Cypress, 2018; Khan, 2014; Sutton & Austin, 2015). Patton (1990) writes, "Perhaps nothing better captures the difference between quantitative and qualitative methods than the different logics that undergird sampling approaches. Qualitative inquiry typically focuses in-depth on relatively small samples, even single cases selected purposefully" (p. 169).

Stake offers a few general guidelines to help researchers in selecting cases (1995). His first criterion asks researchers to consider maximizing what they can learn from a case. In my study, I had three primary criteria for inclusion: (1) parents must have already experienced the transition process with their child and have graduated from high school; (2) the young adults must have received a primary diagnosis of autism spectrum disorder according to DSM-5 criteria given by a trained psychologist, psychiatrist, or medical doctor; and (3) the young adult must be currently employed in CIE or have been recently employed in the past.

Stake's second recommendation for selecting cases relates to time and access to undertake fieldwork and the need "to pick cases which are easy to get to and hospitable to our inquiry" (1995, p.4). I used a purposive sampling approach to recruit participants by reaching out to people in my personal, social, or academic networks (Khan, 2014). In spite of my broad network, it was more difficult than I anticipated to recruit parent participants. Initially, I emailed two therapists my son works with and asked them to forward a recruitment email to parents that they thought would be a good fit for my study. The email acknowledged that the study fulfilled a requirement for a doctoral degree and included my contact information if they wanted contact me directly.

After waiting several weeks, I received only two confirmations from parents who expressed an interest in participating. While I scheduled those interviews, I also reached out to my other networks, including contacts I made during my DePodesta and MNLEND Fellowships to help with recruitment. That led to three more parents who were willing to participate. I now had a total of five participants. Unexpectedly, one of the participants decided she was unable to participate because of family illness. Rather than trying to recruit more participants, I decided to proceed with the interviews I had scheduled.

Stake's final recommendation conveys the importance of criterion of representativeness by including cases that represent a variety of pre-specified characteristics or attributes. I decided to schedule the other interviews while waiting to see if any other potential participants contacted me. During my third and fourth interviews, both parents mentioned another young man and his mother who was a mutual friend of both families, and where the son was also autistic. After the fourth interview was concluded, I asked the parent if she would discuss my study with the new parent, and make an email introduction if she was interested in participating. To my delight, the parent did contact me, and I scheduled the final interview a few days later.

Prior to each interview, I emailed study parents a copy of the consent form, so they had adequate time to review it before we met. At the beginning of each interview, I carefully went over the consent form, emphasizing confidentiality of data, and highlighting the process I would use to ensure anonymity of their data after the interview process. I also assured them that while the topic at hand was personal and may bring up feelings of emotional turmoil, the interview could be stopped at any time with no risk to them.

Interviews

The bulk of data for this study was collected through interviews which Cypress (2018) describes as “a conversation with a purpose” (p. 303). My interest in the topic also meant I paid attention to the recommendations of Fontana and Frey (in Denzin & Lincoln, 2005), when they state that interviewing always has historical, political, and contextual connotations, and that “gaining trust is essential to the success of the interviews” (p. 709).

At the beginning of my study, I developed a series of semi-structured questions as a general structure for each interview, which also allowed me to consistently collect certain information across cases. After the first pilot interview however, I realized that the storytelling aspect of narratives meant while parents answered all questions with some level of detail, they did not necessarily answer them in the same order, and some responses needed a few probes to solicit a more focused answer. Other questions, however, needed to be reformulated to be relevant to the phenomenon I was studying (Merriam, 1998). Interviews started with a disclosure about my own background and experience as a parent of an autistic young adult to build trust, and eventually proceeded to ask for more detailed information about their own child's background, transition and job preparation experiences, other mental health diagnoses, and challenges with employment. Throughout this process, I periodically reviewed my fieldnotes, remained flexible to emerging themes, and planned to pursue specific leads in the next interview based on my observations and issues that were raised.

Scholars agree that the environment plays a crucial role in the interview process (Cypress, 2018; Khan, 2014; Sutton & Austin, 2015). Thus, interviews were scheduled and conducted at locations where parents felt the most comfortable talking about their experiences. Interviews varied in length from 60-90 minutes. Before interviews, I reiterated my study purpose to participants, confirmed acceptance to record the interviews, and asked for permission to take notes related to observations or in-the-field impressions based on what parents shared. Sutton and Austin (2015) reiterate the importance of field notes which allow the researcher to capture nonverbal cues and provide important context during the data analysis process. Since I also disclosed my own status as the parent of an autistic young adult, I was careful during the interview not to use subtle cues that may have influenced any outcomes or findings (Cypress, 2018). During some interviews, parents used the words "you know what I mean" and I asked them to elaborate in their own words what they meant. Interviews were recorded using Audacity, an audio editing software free to use for University of Minnesota students and staff. After each interview was concluded, I used Rev.com software to transcribe data, anonymized names and other identifying data, and then sent a copy of the transcripts to each parent to review the accuracy of the data. After data analysis was complete, I sent a copy of themes from the data to parents for member checking. While not all parents responded, the ones that did confirmed that the themes resonated with them and did indeed represent the information shared.

Rigor

Cypress (2017) affirms that rigor is an essential concern in qualitative research and "is a more difficult task when dealing with narratives and people than numbers and statistics" (p. 254). In qualitative research, rigor is addressed through the concept of trustworthiness which refers to the "quality, authenticity, and truthfulness of findings of qualitative research" (Cypress, 2017, p. 254). Merriam (1998), referring to the work of Lincoln and Guba, proposes using the analogous terms of credibility, transferability, and dependability to achieve trustworthiness.

Interviewer Credibility. Credibility is a form of internal validity in qualitative methodologies. Starks and Trinidad (2007) write that qualitative research is "inherently subjective because the researcher is the instrument for analysis" (p. 1376). This is echoed by Cypress (2018) who adds that relationships leveraged in personal, social, and academic networks are the vehicle by which the study is completed. As a member of a parent group with autistic children, the language used to discuss our children's abilities and challenges was familiar to me, so in conversations, I was careful not to use or interpret common words or phrases used by parents of autistic children, and instead ask for clarification in the parents' own words. After the interviews were transcribed, I emailed copies back to parents for verification. My member checking process also included sending preliminary themes to parents to see if it aligned with their understanding of their experiences.

Transferability. In qualitative research, transferability can be considered synonymous with generalizability and external validity in quantitative research. However, transferability is a difficult proposition to attend to as human behaviors or interactions are never static (Cypress, 2017). Merriam (1998) argues that the value in qualitative research is that it seeks to describe and explain the world as those in the world describe it; thus, the value of case study is in the case itself. However, Dick (2014) argues that case study should serve another purpose, describing case study research as action research, possessing the ability to "bring about improvement in some social situation" (Dick, 2014). In this research study, transferability was enhanced by using a purposive sampling method and providing a thick, description though a detailed description of parents and their child's lives, and also by continuous referral to the literature.

Dependability. Dependability in qualitative research is akin to the notion of reliability in quantitative research, per Lincoln and Guba (in Merriam, 1998). I have used several of Merriam's techniques to ensure that study results are dependable. Dependability was achieved by having two other qualitative researchers in my university department [Department of Family Health and Wellbeing] review transcripts to validate themes. Stahl and King (2020) describe this as "asking for participants to member-check but with peer-level members" (p. 27). I also continuously used the techniques of reflexivity throughout the study process. While setting up interviews and during the interviews themselves, I was candid about the liminality of my position – that of parent following a similar path, and also as a researcher/practitioner seeking to explore what contributed to the different outcomes achieved by their children. My strategy was to present myself as a parent with similar experiences, but also as a research/practitioner who is looking to understand and describe the experiences of others. I attempted to be mindful of my own biases, assumptions, and beliefs that I brought to the study but was also aware that complete reduction was not possible (Cypress, 2017).

Data Analysis

Qualitative data analysis is not a linear process that follows data collection; rather "collection and analysis should be a simultaneous process in qualitative research" (Merriam, 1998, p, 123). In this study, starting with the first interview and continuing through the end of the study, my data analysis process involved taking each new impression apart, and closely examining it for elements that were related to the obtainment of CIE (Creswell & Creswell, 2014). Interviews were the primary means of data collection and through them, I was able to gather information from parents on a range of issues related to their child obtaining CIE. Parents provided expansive information, so data analysis also involved winnowing data; i.e., "focusing in on some of the data and disregarding other parts of it" (Creswell & Creswell, 2018, p. 192). In the data analysis stage, Sutton and Austin (2015) also remind researchers of being true to the participants. Thus, it was important to me to find a way to center the unique experiences of each parent and child through the use of rich, thick description.

Transcription

I used Rev.com's automated transcription feature to transcribe all interviews. I recorded all interviews using an audio-recorder for in-person interviews and Audacity for zoom interviews. Audio files were uploaded to Rev as an mp3 file to my password protected computer where Rev's software was located. After removing filler words from text, I re-read the transcription to correct spelling and other errors. I also anonymized first names, school names or districts, and other personally identifying information.

Reading and Reviewing Interviews

The emergent nature of qualitative research often lends itself to the researcher getting a better feel for the participant's experience of the phenomenon in the first few interviews. I uploaded audio files to Rev the same day as interviews were conducted and read them through so I could correct any errors while the memory of the interview was still fresh in my mind. After that, I re-read them, cross-checking with field notes, and observations noted during the interview process. Each interview presented an opportunity to follow up on topics mentioned by the previous parent. Sutton and Austin (2015) stress the importance of considering what is expressed verbally, but also what is not said, and where even silence carries meaning. This makes the use of observation and field notes during interviews important in creating a complete picture.

Coding, Theming, and Cross-Case Analysis

Coding is a way of indexing or mapping data that allows the researcher to make sense of dense data that often accompanies questions asked in qualitative interviews (Elliot, 2018). Saldana refers to a code as "most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and /or evocative attribute for a portion of language-based of visual data" (2013, p. 3). Charmaz further described coding as the "critical link between data collection and their explanation of meaning" (In Saldana 2013, p. 3).

NVivo software was used to manage transcriptions, and to some extent, help with the coding process. I used a hybrid coding approach as described by Swain (2017), combining inductive and deductive coding methods. Deductive codes were based on my interview questions and review of the literature. As an example, sections of my interviews included codes such as "post-secondary education" or "related to parent expectations". Inductive codes helped me remain flexible to what the data was "telling me", and add new codes as I worked my way through the transcript. As an example, several parents mentioned their child's thoughts and emotions at workplaces led them to feel excluded, and where their child believed the exclusion was related to their autism. I coded these as "autism self-awareness".

I used Miles, Huberman, and Saldana's two-cycle framework to construct themes from the data, starting with within-case analysis. Crowe et al (2011) also note that collective case studies require individual case component analysis or within-case analysis before making comparisons across cases. The process for coding data involved the following: I first read the transcript delivered by rev.com as a word document. After anonymizing the data, I uploaded it into NVivo and re-read it several times to familiarize myself with details of the case. Then I used software features to add my deductive codes and make initial comments on what I thought were the most striking elements of the data. At times I used 'in-vivo' coding, which relied upon the use of participants' own words, rather than my interpretation of the data.

Because each interview was between 60-90 minutes long, with transcripts each averaging 25 pages, I needed some way of organizing some of the events described in each case. I found Yin's time-series technique (2012) to be helpful in assembling key events in each case. For instance, each young person experienced a series of short-term, unsatisfying jobs after high school. Additionally, four of five parents had also rejected the secondary transition offered by their school in search of a better educational fit for their child. By laying out each case in a time sequence, I was able to see that there were similarities present in (almost) each case which help with identifying patterns across cases.

In second-cycle coding, I started making more detailed comments about patterns I was seeing within each case, and started putting coded data into categories. Categories from each case were analyzed to look for larger categories that encompassed choices steps parents made after high school completion, how they accessed services for their child, and experiences that contributed to the attainment of CIE. I completed the same processes for each interview, and after I finished coding the fifth and final interview, I went back to the first one to see if codes that I added in later interviews were applicable. This kept my analysis circular (Swain, 2017).

Cross-case analysis helped with developing themes, which is the process of weaving together categories across multiple transcripts to form a larger idea. A theme, at its' core, is a meaningful pattern identified by the researcher through sense-making of the data, and can be linked back to extant literature from other researchers. In utilizing a collective case study approach, Merriam (1998) states, "one increases the potential for generalizing beyond the particular case" and that "interpretation based on evidence from several cases can be more compelling to a reader than results based on a single instance" (p. 154). In cross-case analysis, I compared and contrasted large categories from all five cases to highlight what was alike and different among cases with regard to patterns,

Participant Narratives

After each interview was complete, I pulled out prominent stories and themes that aligned with the interview guide questions and wrote short narratives for each participant. These narratives are presented in Chapter Four. While there were similarities across each case (for example, an early autism diagnosis between three to four years old), I focused on highlighting the education and early employment experiences of each young adult as shared by their parents.

Summary

In this chapter, I discussed the use of case study design as the appropriate approach for exploring how parents helped their autistic children navigate post-school transition and obtain competitive, integrated employment. I expanded on my epistemological dispositions by examining my role as researcher as well as any inside perspective and relationship to the phenomenon I possess. Chapter Three also brought my methodology full circle by outlining the methods and procedures that guided my data collection process for this case study. Chapter Four presents each parent’s story about their child’s transition experience.

Chapter Four

Introduction and Overview

This case study aimed to develop an understanding of how parents of autistic young adults navigated education, supports, and social services post-high school to help their children find competitive, integrated employment (CIE). The research examined parents' perceptions of their children's educational experiences, their expectations for their child's futures, and their role in their child's employment experiences. Using a narrative approach, a summary of each young adult's story related to education and work experiences is shared in this chapter.

Description of the Cases

Five one-to-one interviews were conducted with parents of young autistic adults. Two interviews were conducted in-person and two were online at the request of the parents. While research and data document the high employment/underemployment rates in autistic communities as well as over-representation in minimum wage jobs, this study sought to give voice to the families that have navigated a different experience, leading to CIE. Each parent and young adult were assigned pseudonyms to protect their identity. Similarly, identifying information about city and school were also generalized to suburb and school district to protect the identity of each family.

Interview 1 – Trish, Parent of Hugo and Ross

As a fellow parent of an autistic son, I first met Trish about eight years ago in a social skills development group for autistic teenagers. Trish and her husband have three children, a daughter and twin sons, Hugo and Ross, both of whom are autistic. While the boys are identical twins, in the years I have known them, I had noticed, and Trish confirmed, that they have different support needs. Her boys are currently 27 years old and live semi-independently in a supported environment a few miles from their family home, in a city about 30 miles west of the Twin Cities metro area. Ross has worked in multiple settings since high school, while Hugo has only worked in sheltered employment. I may refer to the twin with greater support needs, Hugo, sporadically, but the focus of this summary is on Ross. Growing up, both boys attended elementary school together, but in middle school, their paths diverged. Ross continued in a public middle school, but Trish and her husband made the decision to send Hugo to a program with greater one-to-one support services. Eventually, Hugo came back to finish high school with his brother. Trish expressed uncertainty that they had made the right decision for Ross by keeping him in a regular school program.

> *Not to just think you really just need to go to a typical school and be integrated. They can always come back to that, you know, to do something different. But because it might help them down the road to develop their social skills in a good manner as they're coming along, rather than it's too fast for them or, or you know to do it at their level and at their speed that they need it to be at.*

Trish reinforced the importance of having an advocate through big transition events; in her family, Arc of Minnesota a non-profit organization that supports the rights and wellbeing of individuals with disabilities was their advocate. When the boys were younger, Arc asked to have a planning meeting with people that were relevant to the boys' lives. They did this separately for each twin, and used the overarching question of what expectations existed for the future, both from the perspective of each boy, but also family and friends. Both boys expressed that independence was their main goal. Trish said that they still use that planning sheet to this day and refer to it occasionally as interests change and as the boys continued to get older.

Both boys experienced the same activities, such as Special Olympics, Bocce ball, bowling, etc. as their mother believed that socialization was an important skill for them to have. In conversations I have had with both boys, I have noticed that Ross is very outgoing and talkative and Hugo quieter. This difference in personality, along with their support needs, may have also played a role in the types of jobs they were able to pursue. In high school, Trish shared that Ross expressed a desire to have more spending money and with the help of some networking from his father, got a job working at a large restaurant and entertainment complex. Trish expressed concern with the environment, which was primarily customer facing, but it appeared that her concerns were unfounded. At first, Ross mainly worked in the back doing dishes, but gradually asked for more responsibility, including working out front with customers, taking food orders, and recommending different games to customers depending on their interest and ages. Ross worked there from his senior year in high school till the start of the COVID-19 pandemic, when they closed temporarily, and then permanently.

His next job was at a local big box store wiping down carts during the height of the pandemic, but he didn’t enjoy it, and communicated to his mother that he wanted more of a challenge. After that experience, he went to a burger and ice-cream restaurant, but that too did not last long because of his interactions with the day-to-day staff and lack of support from the shift managers. In all his work experiences, Trish shared that having a supportive and communicative manager/supervisor is essential.

> *Yeah, and that's staying very connected to that supervisor and knowing that that supervisor understands our kids is a make or break as far as I'm concerned. So he went over to [restaurant] and the owner understands, but not the managers that were there on a daily basis. So as time went on not that they wanted him to stay, but Ross could feel like they were being demeaning to him and it's not the way he wanted to feel.*

Finally, after that experience, Ross started working at another restaurant/entertainment center located five blocks from his current supported living housing. Similar to his high school job, he works out front with customers, and is open to helping out in any way he can, including going into work early. When asked about what expectations she had for her boys' future and what sort of jobs she would like to see them in, Trish shared that her goal was to see both boys enjoy the work they do and be appreciated by the people they work with. To that end, while there was not a type of job that she considered ideal for either boy, what was most important was a job that would help them with attaining independence as this was both boys' main goal.

> *So it's his kind of thing. It's the arcade. I don't know all that sensory stuff. I don't know how that just doesn't blow him away, but he really enjoys it. But the people, there again, the supervisors are very appreciative of him. And so then Ross goes over and above to try to help other departments and do different things. I don't look for them having to have a certain job one way or the other. Okay. I just really want them to feel that they enjoy it and they're appreciated by the people around them.*

We also spoke about the role of Transitions programming in helping the boys build life skills, achieve CIE, and work towards independence. Trish shared that most of those experiences were related to jobs that required lower skill level such as stocking shelves at the grocery store, folding towels at a hotel, or cleaning at different businesses.

Through transition programming, the boys learned some skills related to working, such filling out timecards, and balancing a checkbook. While they were varying degrees of success in learning those skills, it did help Trish realize that it was better to spend more time on skills that would help them achieve the independence they were both working towards, and find more supports for the ones they couldn't. For instance, Trish noted that both boys are vulnerable with money and finances, so for now, Trish and her husband are the boys' guardians, helping them pay bills and sign the lease at their current housing.

Towards the end of our conversation, Trish offered words of advice for parents of younger autistic children, namely "it's never too early" to start planning for their future and to consider what other resources might be available for education and social services. For Trish and her husband, since the boys asserted that independent living was their goal, they spent the greatest amount of time ensuring that the boys had the tools they needed to become and remain independent. As of now, Ross works 25-30 hours per week, enough to afford an apartment with his brother, and still receive Social Security income. He would like to work full-time, but so far, Trish is hesitant. She worries that he will quickly become overwhelmed and not have the stamina to work a full work week, and put his job at risk.

Interview 2 – Andre, Parent of Jesse

I met Andre in 2018 through a mutual colleague. At that time, his son, Jesse, was finishing a program to become a train conductor and I thought that was so impressive. Andre and his wife, Sonja, have three children, and their eldest Jesse, is 28 years old and autistic. When early childhood family education (ECFE) offered Jesse's initial autism diagnosis at three years old, the teacher offered the opinion that he may never learn to button his shirt or speak proficiently. Jesse's diagnosis was devastating to his parents, and they made the decision that Sonja would be a stay-at-home parent coordinating intensive therapies focused on cognitive and physical development for Jesse. While it would have been preferable to speak with Sonja, my point-of-entry to this case study was through Andre.

Andre's experience with their school district's autism programming was extremely positive. Starting in preschool, a bus would pick Jesse up three to four times a week and take him to therapy. In elementary through high school, he was mainstreamed for most of his classes, with his IEP providing modifications for more language and communication support. In their household, working was an expectation, and Jesse himself expressed a desire to work. Andre's pride in his son is apparent and he even shared Jesse's nickname in middle school, 'Braveheart', given to him by school staff "because he would be afraid of things and do it anyway".

Jesse's demonstrated an early and sustained interest in trains, and he was determined to pursue a career in the rail industry. After high school graduation, he did not attend comprehensive transition planning offered by his school, opting instead to obtain railroad conductor certification at a local community college. While he was able to obtain certification, making the leap into the working world was more difficult. When I asked about their experience with Vocational Rehabilitation in helping Jesse find and prepare for a job, it appeared to be limited to skills related to showing up early, dressing appropriately, etc., versus finding a job. Andre also shared some of Jesse's experiences at his rail interviews. While it was not explicitly stated in our interview, Andre also shared that there appeared to be some bias against Jesse and his ability to navigate relationships.

> *And he made the decision with us to say, mom, dad, I - he's very self-aware, you know with his autism - I have a hard enough time maintaining relationships. I don't want that on top of that. So I want trains to be my hobby where I have fun and work elsewhere.*

After that, Jesse signed up with a temporary placement agency which sent him to various jobs that would never become permanent, and capped hours just short of being eligible for benefits. Jesse was still living at home, so Andre was able to witness his son's agitation at the lack of structure and routine. It was at that time, that a family connection with the CFO of a robotics parts manufacturing company gave Jesse the opportunity to interview for a Kit assembly technician, a job that would allow him to capitalize on his second favorite interest, Legos.

Jesse has now been in his role for six years and was just recently made the supervisor of the Kit assembly department. Andre recently had an opportunity to spend a day with Jesse at work, speaking to other employees, and paying attention to the company culture. He was pleased at the stable nature of the industry, the kind comments about Jesse from his co-workers, and the decades-long anniversaries that many employees seem to enjoy. Despite this, he expressed hesitancy about the future.

> *The benefits are good. They really seem to be focused on their employees. Their market seems to be strong and dependable so that it's not like he's going get laid off out of no fault of his own, it seems. And I keep telling him, you know, you may get laid off through no fault of your own. And that's a big transition to have to go through. So just be emotionally prepared that that could happen.*

Both Jesse's parents appear to be tenacious advocates for him and in true full-circle fashion, Jesse has become somewhat of an advocate himself.

> *Sonja is a very, very strong advocate for Jesse, just a bulldog advocate. And he has done in part so well because of Sonja's advocacy to the point where one of his coworkers who now reports to him was saying something about work and it was a concern that she had. I can't remember what the subject matter was, but Jesse said something to the fact of, well, Mary or whatever her name was, I can't remember. Well, you need to advocate for yourself.*

From Andre's narrative, I learned that Jesse lives with a roommate in a first-ring Minneapolis suburb with a short commute to work. He is also very engaged politically and has made friends through these associations. Again, Andre's pride in his son was apparent as he shared that Jesse will soon become a local delegate for the party he supports. Truly a far cry from the young child who could not button his shirt.

Interview 3 – Ellie, Parent of Mark

Ellie was connected to me through my previous fellowship experience with the director of an employment services agency that works exclusively with people with disabilities, MindShift. Her son, Mark, is 24 and very close in age to my son. We met for the first time through Zoom. Mark is the younger of her two children and as a nurse, Ellie knew that Mark's development was different from that of his older sister. Ellie has learned to be a very strong advocate for her son. When Mark was two, she pushed their pediatrician for more testing and a diagnosis, but the diagnosis of autism did not come till he was about three years old. Soon after, Ellie was connected to ECFE and started Mark on an intense regimen of Applied Behavior Analysis (ABA) therapy from three to six years old. She credits ABA with helping him "come out of his shell". In addition to

Mark’s autism diagnosis, he also has other co-occurring mental health diagnoses which have contributed to difficulties during adolescence.

Ellie’s advocacy for her son was apparent throughout our entire conversation, describing herself as a “tiger mama”. At multiple points, she did not hesitate to share when she felt that Mark was not receiving sufficient or appropriate services but acknowledged that some therapies and services meant to be provided by schools were hampered by lack of funding. While Ellie expressed some appreciation for her school district, she was less positive about their experience with Voc. Rehab, describing their services as more exploratory, versus training or actual job placement.

> *We sort of got hooked up with VR or Voc. rehab in high school and I don't have great things to say about them. I don't find that was a positive experience… One benefit I say we had, is, he got to go down to Southern Minnesota to explore some different possibilities of what he might want to do for work. I think he spent a few days down there with the family, some program they have down there, but it didn't develop into any job placement at all. It was more just like, we think Mark could do this.*

In sharing her son’s story, Ellie also shared that Mark has found it difficult to embrace his autism. She credits Minnesota Independence College and Community, a life skills program offered post-high school for young adults with disabilities with helping him embrace his autism and teaching him life skills. Earning a certificate through this program helped boost Mark’s self-esteem and desire to find work. Their experiences with Vocational Rehab led Ellie to help Mark find jobs herself, including helping him interview at a national big-box retailer which was disastrous, and finding him jobs cleaning at several local businesses. According to Ellie, Mark loves to work and “finds identity with his work, and gives him a sense of purpose”. In parallel, Ellie also believes that Mark should be able to work as much as he wants to and be a “contributing member of society”, rather than working part-time and relying on Social Security Disability income.

Ellie is highly connected with different types of resources, which led her to MindShift. This employment services agency places employees with disabilities in jobs around the state. Some of these jobs have a high turnover rate due to the repetitiveness of the role. Some autistic individuals, however, thrive in this type of environment and role structure. What is unique about MindShift is that it remains the employer of record, contracting individuals to different business, and providing on-going job coaching services to the autistic individuals, and training for the businesses. She found MindShift to be highly supportive as compared to Vocational Rehab, which only offered “natural” supports to any job Mark obtained. She defined natural supports as “other people that work there will help him” but at the same time, did not provide him with a job coach. In comparison, the job coach assigned to Mark through MindShift continues to be available to him, including helping him navigate a potentially difficult situation at work.

Mark has worked as a MindShift employee contracting at an international medical device company with manufacturing located in the Twin Cities. According to Ellie, he loves where he works, which coincidentally is where his dad is also employed. While he has his license and can drive, Ellie is nervous about letting him drive to work by himself. Mark still lives at home with his parents but has not voiced the desire to live independently yet. When questioned about when and how that would happen, Ellie believes that Mark needs to see examples of other young people like him being independent but was more ambiguous about what she would need to see in order to feel comfortable making that happen. Another consideration is that even though Mark works full-time and is paid competitively, it is still not enough to afford the cost of one-bedroom apartments by himself in the Twin Cities or its' suburbs.

Ellie recognizes the challenges of parenting an autistic child. Still, several times in our conversation, she mentioned the "blessings" their family has received that allow them to provide Mark with high quality services. She credits MindShift with advocating for Mark to work a full 40-hour work week, but as an employee of MindShift, can take advantage of their generous vacation policy when he needs some time away from work. At the same time, she doesn't believe that this job is the best fit for him, because as a nurse, she is aware that any repetitive motions such as those that make up most of his work, put him at risk of injuries and strains. She also wishes that his job provided more socialization. Ellie also recognizes the dearth of social support services for children like Mark. To that end, she has created her own company to provide independent living services for young adults looking to establish independence. As she said to me at the beginning of our conversation, if you can't find what you need, create it,

Interview 4 – Lee, Parent of Milo

I was also introduced to Lee through MindShift and connected with her on Zoom. Our conversation lasted the longest, and at several moments, Lee used the words "you know what I mean" which led me to believe that my own experience as the parent of an autistic son validated both her experience and lessened the need to explain what she meant by some behaviors common to autism. Her son, Milo, is 26, and has worked for the past two years at the same international medical device company as Mark. Milo is the second of three children and when his parents divorced when he was 12 years old, shared custody meant that Milo and his siblings spent alternative weeks at each parents' house. Lee shared that her ex-husband worked long hours and it may have contributed to a lack of structure and schedule at his house, and while Milo is adaptable, he does better with a consistent schedule.

> *Unlike the stereotypical person with autism, he can roll with change pretty well. I mean, he'll let you know if he is not happy with the situation that's going on, but for the most part, he really handles, uh, change in plans fairly well. Even though Mx rolls well, he does well with lapses in routine, he thrives when there's structure.*

Lee noticed that Milo was not reaching the same milestones as his older sibling and had also started to develop echolalia, which is a repetitive, sensory motor behavior evidenced by individuals imitating the speech of others (Chown & Beardon, 2017). Milo also received intense early intervention through ABA and complemented with other therapies as needed. ABA is "a science of human behavior" (Pennington, 2022, p. 315) that has been used therapeutically with autistic children as well as those with other developmental conditions to reinforce positive and desirable behaviors. Lee describes her son as "curious and pretty funny" with an ability to "hyperfocus" on subjects that he is interested in. She also noted that it is extremely important for her son to be liked by others, that independence was a goal for himself, and that he wanted a college experience like his siblings. In high school, Milo was mainstreamed for most of his classes, with his IEP providing extra help in a few classes.

Milo had several part-time jobs through high school and up to age 22, worked at a local bar and grill, an auto body shop, and seasonal employment with the City's Park and recreation department. Lee stated that all these jobs were competitively paid but did not require a great deal of skill; consequently Milo expressed a desire to do more, with his ultimate goal being independence. At the same time, he was approaching high school graduation and Lee realized that for him to achieve independence, she would need to help him learn some of the bigger skills required in a systematic way. Since it was important to Milo to have a college-experience like his siblings, after high school he attended Bethel University Inclusion and Learning Development (BUILD) program for two years. Going to BUILD was intentional as Lee explored and decided against Milo going to 18-21Transitions programming.

> *We got him in Bethel in the Bethel Build program because I had looked at Transitions Plus and the students that were in that program and he just had more; he was just higher functioning than at least the students that I saw. And his teacher, his special ed teacher in high school also thought that he would've outgrown the program pretty quickly and that he might've been bored. And again, he would've been living at home, and he really wanted to go away to school.*

BUILD helped develop Milo's independent living skills and provided several paid internships during his two-year attendance. After completing this program, Lee learned about the services that MindShift provides and connected with them for Milo to go through their employment services program. After BUILD, Milo explored several supported living situations, but decided to move back home because of inconsistent staffing and the frequent check-in's with staff required to live in supported housing.

Lee and Milo’s experience with Vocational Rehab was very positive and Lee expressed gratitude for the care demonstrated by the staff.

> *I would say they were very client centered for him and were always asking, well Milo, what do you think? What would you like that, tell me why you would like that, tell me why you wouldn't like that. So they, they did a really great job of asking questions.*

At the same time, Lee emphasized the importance of teaching Milo skills that were missed by Voc. Rehab, such as showing up to work a few minutes before his start time, and learning how to build relationships with his co-workers. Milo’s varied work experiences also helped prepare him for his current role. He first started out as an employee of MindShift contracting at the same medical device company as Mark. Recently, he transitioned from a MindShift employee to a full-time permanent employee at the medical device company, earning benefits and a competitive wage that allowed him to achieve the type of independence he has been working towards for a long time. As part of this journey, Milo is most excited about his ability to start his own retirement account, something he heard his parents talk about as he was growing up. He has recently secured an apartment with a roommate about a mile from work, and since he drives, can get to work very easily.

At work, Milo has a mentor who is his go-to when he needs questions answered, and a supervisor who also has a child on the autism spectrum and is patient with Milo’s speed of work. Even so, Lee remains concerned that things get missed. She has set up informed mail delivery so she can track Milo’s mail because he doesn’t always open and respond to things. As part of being made permanent in his current role, Milo was supposed to make selections related to medical benefits which he missed. Fortunately, the supervisor knew to contact Lee as a backup.

Milo’s relative independence is new; he moved into his apartment with his roommate in October 2022. The apartment is also very close to Lee’s home, and both mothers alternate weekly check-ins on the boys, making sure they have enough food, and the apartment is clean. Lee, like the other parents I spoke with, voiced concerns about Milo’s future. For one, she worries about his full-time employee status at the medical device company, because with MindShift as his employer, there was someone to advocate for him and she would also receive reports about Milo’s progress. Her advice to another parent is to “invest on the front end” and “keep positive because they surprise you every day.”

Interview 5 – Annie, Parent of TJ

I was introduced to Annie after my interview with Lee. Annie and Lee met through an autism parent support group when their sons were younger and continue to be active attendees. The families appear to have a close relationship, especially when the boys were younger, so it made sense when Lee brought up the idea of the boys living together. TJ and Milo are now roommates, living in an apartment close to Lee’s home in the Twin Cities Northwest suburbs. Like Milo and Mark, TJ also works at the same medical device company, and has worked there for about a year.

TJ is the oldest of Annie’s three children, and even as a new mother, she had a certain sense that his development was different from other children. She shares a memory from an early childhood classroom,

> *We went through EF, what was it? ECFE classes. And, you know, the group of kids were playing at one end of the classroom, and he would be over there. And I'm like, that seems strange, you know? So, back then the teacher's like, well, we can't diagnose anything, but you know, I would talk to your doctor about it.*

After more than a year of consulting with doctors, TJ was diagnosed as autistic when he was four years old. One doctor even told Annie that she should put TJ in a group home because "he won't be able to achieve or do anything". She remembers how that made her feel,

> *I felt pretty crummy being a first-time mom and TJ was pretty hyper too back then. He'd be in the background turning on light switches and all that. You know, <laugh>, licking the doorknobs, all the fun things. <Laugh>. I felt terrible you know; that doctor made me feel crummy. I mean, I knew, I wasn't going to do that, I'm not going to put my kid in a group home.*

In contrast to that earlier description, when talking about TJ now, Annie frequently used the words "high functioning". TJ's high functioning in school was what led his parents to decide against sending him to his school district's transition program, opting instead to send him to Bethel's BUILD program. After observing some of the transition program classes, she decided that the skills taught were too low level for TJ, and this was not the right fit for him. In an attempt to find the next thing, after high school graduation, TJ attended a nearby community college. This was unsuccessful and he only lasted one semester, as he needed more supports than the college was able to provide for him. It was then that Lee mentioned Milo's acceptance at the BUILD program; Annie decided to apply on TJ's behalf. At first TJ did not want to attend, believing that the other students would not "be like me". Annie shares,

> *Well, we signed him up to go and then he went there for two years, and he absolutely loved it. I mean, it was amazing. He came out of his shell. He was depressed for a few years...He made a lot of friends. He still has those friends.*

Annie describes TJ as having “a busy vibe” and being very outgoing. He likes to be active and has participated in Special Olympics for many years. In recent years, TJ has been an informal and more recently, formal advocate for the program. He has been interviewed on TV several times, and even acts as a spokesperson for the program, talking to various schools about the importance of adaptive sports. In fact, Annie said that TJ’s dream job would be to work for Special Olympics.

Annie recalls TJ’s IEP goals were mainly related to developing more social skills and becoming independent. In 2020, TJ had been accepted into a supported housing apartment, but the start of the COVID-19 pandemic meant that was no longer an option. For the next several years, TJ continued to live at home, and worked with a job coach through Autism Works to find and apply for jobs through the want ads. The other jobs they helped him secure were working at a large full-service grocery store and then as a host at a restaurant. They also connected with Vocational Rehab and while Annie did not offer the same disdain as Ellie had in her interview, when most of the jobs Vocational Rehab identified for him were custodial positions, Annie commented, “he’s worth more than that”.

Annie applied twice to get TJ approved for Social Security but both cases were denied by the appointed judge. Annie refers to the words high functioning again to describe the judge’s reasoning. Her worry and disappointment are evident as she shares that social security income would have helped with a large portion of TJ’s rent. TJ pays half the rent on the apartment he shares with Milo. His job at the medical device company is approximately one mile from the apartment, and while he currently takes Metro Mobility to get there, Annie has encouraged him to think about running or biking in the spring and summer.

Towards the end of our conversation, Annie expressed optimism about TJ's future and described him "thriving". He is on track to become a permanent employee at the medical device company and would then be eligible for a pay raise, as well as medical and retirement benefits. His outgoing nature has helped endear him to his co-workers and he has made friends at work. Despite this, Annie has mixed emotions about TJ's journey to get where he is now. She mentioned several times in our conversation, the quickness and relative certainty in new autism diagnosis, compared with her experience in getting TJ diagnosed. She also talks about the expenses related to TJ's speech and occupational therapies, not covered by insurance at the time, and subsequently paid out-of-pocket. Annie also noted the number of resources that are available to parents with young autistic children nowadays and wishes there would have been more resources available when her son was younger.

Like Milo and Mark, TJ got his current job through MindShift. Annie describes the time after graduating from the BUILD program and his current job as "three, four years wasted" and wished she had heard about MindShift earlier. While TJ is "doing great" and Annie is "really proud of him", there is a sense that with more resources, he could be further along in his path to independence. The following table is a profile of all five young adults to serve as a reference for the remainder of the dissertation.

Table 2

Summary of Young Adult Outcomes

Young adult/parent	**Age**	**Post-secondary education**	**Current housing**	**Work**	**Interests**
Ross/Trish	27	None	Supported housing, independent with roommate	Part-time 32 hours/week Restaurant/Entertainment	Playing video games, Special Olympics
Jesse/Andre	28	Community college, Rail conductor certificate	Independent, with roommate	Full-time 40 hours/week, Supervisor of kits-assembly department	Trains, Legos, Political interests
Mark/Ellie	24	MICC, Living skills certificate	Lives at home with parents	Full-time 40 hours/week Medical device company	Movies
Milo/Lee	26	BUILD, Living skills certificate	Independent, with roommate	Full-time 40 hours/week Medical device company	Varies, but new interests tend to be hyper focused
TJ/Annie	27	BUILD, Living skills certificate	Independent, with roommate	Full-time 40 hours/week Medical device company	Special Olympics, sports, spending time with friends

Source: C. Silveira

Summary

This chapter provides context and depth to the life and work experiences of each young person as told to me by their parents. The purpose of these narratives is to develop a whole-person perspective of each individual. The next chapter will look at themes that emerged across these individual narratives and will summarize broader findings of this study.

Chapter Five

Findings

"Every child needs at least one adult who is irrationally crazy about him or her."

Urie Bronfenbrenner

This chapter outlines the overarching themes that came to the forefront after a data analysis process following conversations with five parents of young autistic adults who currently work in competitive, integrated employment. By providing information about their experiences advocating for their children's needs, these case studies illuminate how parents helped navigate a path to CIE. The design and use of semi-structured interview questions allowed for exploration of parents' expectations for their child's futures, their role, and that of others in their child's employment experiences. Parents also shared challenges that were experienced along the way, and through their narratives, their children's determination in creating a life of independence for themselves. Each interview was unique and reminded me that the heterogeneous nature of autism means there is more than one way to get to successful adult outcomes.

The use of semi-structured interview questions helped focus experiences on the path to employment, and after further analysis, I was able to construct several themes based on commonalities across narratives. Four major themes were identified through the analysis of the interview data. These themes include: the role, expectations, and advocacy of parents; rejection of comprehensive transition programs; knowledge and resources; and dogged determination. Within several of these major themes, subthemes were identified and also described in this chapter.

Theme 1: The Role, Expectations, and Advocacy of Parents

The role of parents is critical in the transition process (Chen et al., 2019), as they are the ones who have been attending to their young adult's needs since childhood, and continue to be trusted sources of knowledge and resources for transition and adult activities. An interesting finding in this study relates to parent expectations that elicit positive responses from their children, initiating in a 'gain cycle'. This positive 'gain cycle' is one mechanism to understand how the other closely linked themes of parent knowledge and resources, advocacy, and an increased autism self-awareness in their young adult result in positive adult outcomes, including CIE. Merriam (1998) citing the work of Guba and Lincoln, suggest paying attention to "areas of inquiry not otherwise recognized or provide leverage on an otherwise common problem" (p. 135).

The role of a parent takes many forms. The lack of a blueprint in creating paths to CIE for autistic young adults often meant that parents needed to be creative in finding jobs or resources that may help their child find suitable employment that can help them establish independence. Parent expectations have evolved from difficult early years to a more sophisticated understanding of what their child can achieve. Consequently, parents have learned to temper their understanding of success, consider their children's other mental health diagnoses that may exist and affect functioning, but also be mindful of their children's own expectations for themselves. Three sub-themes were identified associated with the role parents play in supporting their young autistic adults on a path to CIE. These sub-themes are: (1) influence of parental expectations, (2) autism self-awareness, and (3) support and advocacy.

The Influence of Parental Expectations

It was quickly apparent from my conversations that employment and independence were two goals important to both parents and their children. Based on information shared in interviews, it appears that each child achieved those goals to some extent. Ross is employed, lives in a supported environment with his twin, and while he cannot drive, has access to transportation and can easily get to work on his own. For Ross, easily accessible work with fewer supports also increases the probability of long-term employment. Jesse has worked over six years as a kit assembly technician and was recently promoted to the head of his department. He lives in an apartment with a roommate, can drive, and is politically active at a regional level. While Mark still lives at home with his parents, he has been employed for two years with MindShift, has his driver's license, and is working on skills that his mother believes will help him achieve independent living. Milo and TJ are roommates and live independently in a market-rate apartment. They work at the same company and while Milo has his driver's license and can drive to work, TJ uses Metro Mobility. They both have unique interests, with TJ heavily involved with Special Olympics, both as an athlete and a spokesperson.

How did these young adults achieve these goals? In my conversations with parents, they were unable to identify exactly what activities or events prompted their children's desire for independence. Certainly, any early expectations were fluid given how the diagnosis of autism can change a parent's outlook for their children's future, and they must now re-imagine what is possible. Andre, Jesse's dad shares,

> *He was diagnosed at three and a half. Okay, that was a punch in the gut. He was our first child. Because he's the oldest and that set our expectations for what our*

> *family life was going to be like. It changed the white picket fence and big house and dog, you know, that kind of picture. We reset what would make us happy. And a big part of that was making sure Jesse could develop as normally as possible and be as happy as possible. That was our fancy house and fancy car.*

As Jesse developed and mastered skills, Andre's expectations shifted from 'Can he work?' to 'What can he do?' to 'What is he capable of?'. He started looking into the different types of jobs that autistic people could do and believed that Jesse's interest in trains was a strength that could be leveraged into a career in the railroad industry. At the same time, Jesse voiced his own desire to work, and knew that if he wanted to pursue a career in the rail industry, the next step would be to obtain related education.

From my conversation with Trish, she was not aware of expressing any expectations of work when the boys were younger. Instead, she emphasized the importance of being "*aware of what our kids need when they're young*" and developing social skills that could help them in many situations. What was more important to her was not where the twins worked, but rather, how they were treated at work and whether they felt appreciated by their supervisors and co-workers.

Trish reflected that she "*my boys might be a little different from other kids like them; they do maintain their jobs*". By that comment, she is likely referring to the high unemployment rate in autistic populations. Since Ross had a job in high school, she believed it was possible for him for him to find work in competitive environments even after graduation. She attributes this ability to find and maintain jobs to the decisions her husband and her made when the boys were in middle and high school. Some of those decisions include, having the boys participate in Special Olympics as one way to develop social skills and peer friendships, and being responsive to the boys' development needs which resulted in Hugo attending a more specialized middle school, and Ross continuing in their district middle school in mainstreamed and special education classes.

Ellie attributes Applied Behavior Analysis (ABA) therapy from changing Mark from a "*little, wild animal*" to "*learning how to communicate with us*". Mark's experience with ABA also changed her expectations of his future. Our conversation suggests that Mark's desire to work may have developed over time and her expectations of his future were influenced by his desire to work. However, she admits that it was difficult to plan for that future because of Mark's refusal to accept his diagnosis of autism. In high school, he expressed a desire to work in a movie theater, so Ellie arranged a job exploration experience of one, but "*it didn't really pan out*".

Lee's preparation for Milo's future started with determining how he could achieve independent living skills, as she knew that having those skills would influence the type of future he could have. She describes his's indecision towards the end of high school as he knew he did not want to attend the comprehensive transitions program (CTP) offered by his school district. Her expectations for Milo's future were also determined by how she perceived his "functioning" and his needs for support.

> *I had looked at Transition Plus and the students that were in that program and he just had more, he was just higher functioning than at least the students that I saw.*

Lee also shared that Milo has a very good "*work ethic*" and although he needs prompting, when "*he has a job to do, he does it perfectly….and he's always wanted to work*". When I probed further about where his desire to work may have stemmed from, she was unsure, saying there might be some financial motivation, "*but I just think he likes to get out of the house and do* *different things*". Later, when she talks about Milo transitioning from a temporary to a full-time permanent employee at the medical device company, she said Milo was very excited to start his own 401k "*because he has heard his dad and I talk about 401k and medical benefits*". From this statement I gathered that even though expectations around work were not overtly expressed in their household, it appears that Milo may have been privy to conversations between his parents about benefits at a job beyond money. This may have a role to play in Milo developing an understanding of work and expectations that he had for himself.

Overall, parents' expectations of their child's future were positive. All felt that their children were currently doing well and would continue to thrive in the coming years. Despite their children's achievements, I recognized a pattern among parents' expressions of their expectations and hopes for the future. During interviews, parents might state how well their children were doing, but then, tempered their statement with fears or uncertainty about what may occur in the future. For example, while Mark displayed a strong affinity for his work, and with the company's mission that they are "saving lives", Ellie does not believe this job is the right fit for him. Instead, she expressed a desire for him to get a job that would provide more socialization with others, and less exposure to job-related injuries associated with the repetitive movements in his current job.

Andre shared his thoughts related to an uncertain future following a visit to Jesse's workplace. His impressions of the company and workplace were largely positive, but then he added,

> *Their industry seems to be strong and dependable, so that it's not like he's going to say, I'm going to get laid off out of no fault of my own. And I keep telling him,*

> *you may get laid off through no fault of your own. And that's a big transition to have to go through. So just be emotionally prepared that that could happen.*

This theme examines how parent expectations have an influence on future work outcomes for their autistic children. Extant literature reports that an early diagnosis of autism can reset parent expectations around many future outcomes, including employment, independence, and social connectivity. Parents interviewed in this study expressed similar sentiments at time of diagnosis, but as their children matured and met developmental milestones, expectations also changed. Nevertheless, even the most positive of parent expectations are tempered with uncertainty for the future that is grounded in parents' own mortality. In some cases, parents expressed a desire for employment that is a better fit for their child's interests and strengths.

Autism Self-Awareness

Autism self-awareness refers to how parents expressed how their young adult child perceive their autism, and their understanding of how it affects their daily lives. Parents also described how their children's level of autism self-awareness impacted the supports they would need to be successful in employment. Five parents shared stories of their children's work experiences. Some of these work experiences started in high school, and all five had a series of jobs that varied in length and type of skills learned, before finding stable employment in their current positions. Through their parents' narrative, these five young adults, aged between 24 and 28 years old, conveyed a desire to work and become independent. The desire to work was expressed in different ways, either because of seeing their parents work, or developing a more mature understanding about the role of work and money in establishing independence.

Andre was the first parent that directly discussed his son's awareness of his autism. At Jesse's railroad job interviews, he learned that the characteristics of his autism related to communication and forming social relationships would not be a good fit for a career in the railroad industry. He was also told that there would be long workdays with unpredictable schedules. Jesse could not reconcile what he knew about autism, with a railroad career that was typified by a lack of structure and a greater social connectivity than he was comfortable with. He then realized that his childhood interest in becoming a rail conductor was beyond his capacity and shared his change of heart with his parents,

> *And he made the decision with us to say, mom, dad, I - he's very self-aware, you know, with his autism - I have a hard enough time maintaining relationships. I don't want that on top of that. So I want trains to be my hobby where I have fun and work elsewhere.*

Andre also mentioned that the metro area is not home to any central rail hubs. This meant if Jesse was offered a job, he would need to move to another state without the support of his parents which Andre stated was “uncomfortable”. When asked to elaborate on who that was uncomfortable for, Andre explains,

> *All three of us Mom, dad, and Jesse realized that it would be hard to set up life at, especially at, he would've been maybe 19, maybe a young 20 at that point.*

What Andre refers to here, is that in order for Jesse to pursue a career in the railroad industry, he would have to leave the area, move to a new city and state, and set up a life there, all without the day-to-day support of his parents. Setting up a new life also includes finding an apartment, learning to drive in a new city, accessing new services, learning new routines, etc., and without his parents nearby to help quickly if needed. This of course would be in addition to learning what was expected from him in a new job. The importance of Jesse’s understanding of how autism affects his life and work choices cannot be overstated. With independence his goal, Jesse knew that it would take a greater effort to pursue a career as a rail conductor, given the supports he would need both at work and in setting up a new life. Given that stereotypes of autism can include a reduced empathy response and ability to recognize and label one's emotions, it takes a profound self-awareness to come to the realization Jesse did that a career in the railroad industry was not for me, and pivot to different employment.

Jesse's self-awareness of his autism is contrasted directly with Ellie's son Mark,

> *Mark has never embraced his autism. He actually hated it. And it took him until he went to MICC. When he went there, I was hoping if he got anything out of it, that he maybe would just have a little bit more awareness of autism and be a little bit more accepting of himself because he doesn't want services. He's always saying, I'm not like them, you know? But he is, he really is. He just doesn't understand that he's high functioning, but just enough to be dangerous.*

Mark fought his inclusion as part of a disability community for many years and refused to be labeled as autistic. For Mark, his refusal to have an autistic/disability identity imposed on him through adolescence was counterproductive to his mother, Ellie's efforts in finding supports and services to help him maximize skills development. She shared that Mark also believed that no one else could tell that he was autistic, but she adds, "he is. He really, really is". Ellie recalls that he "hated" being on an IEP and being talked about in those meetings and refused to attend them. He also "hated" participating in Special Olympics because of what participating in the event defined him as. In high school, he wanted to participate in mainstreamed high school classes, and Ellie found the resources to make that happen, but she noted that it was a struggle because Mark did not connect his autism and corresponding behaviors with a need for a paraprofessional in class. It was not till Mark attended MICC for three years that he finally seemed to have developed an understanding and acceptance of his autism. MICC is a life-skills program based in a Minneapolis suburb, that aims to equip young people with disabilities with independent living skills. In fact, Ellie shared that last April Mark reminded his mom that it was Autism Awareness month, and as a sign of his growth, declared that awareness of autism was not enough, it should really be "beyond acceptance".

Ross' understanding of his autism is be influenced by the decisions his parents made to keep him mainstreamed in middle school, versus sending him to the same program as his brother to receive more 1:1 support. However, Trish questions whether this was the best decision for Ross for several reasons. While Hugo is the twin with greater support needs, she notes that he seems to have more of "a concept of a rounded life, you know, like work life and home life". In establishing independence, she states that Ross would like to work as many hours as possible, and that makes her concerned. These concerns appear to be related to the number of hours he would like to work and experiencing autistic fatigue or burnout. Autistic fatigue and autistic burnout are terms that relate to the susceptibleness that autistic people face navigating social situations and sensory overload. In Ross' case, it would be easy to become overwhelmed while working at a restaurant/entertainment complex due to loud machines and games, and the fast nature of the job. She notes that he doesn't seem to have an awareness of how working long hours are connected to experiencing fatigue or burnout. Trish attributes at least some of this understanding to the person-centered planning approach that The Arc Minnesota, a non-profit dedicated supporting the inclusion of individuals with intellectual disabilities, used with both boys, and where the boys stated that independence was one of their goals.

Annie shared that TJ's understanding of his autism has often resulted in disclosure.

> *He knows he's different from other people. He doesn't mind telling people that he is autistic, you know? He's like, yeah, I'm a little quirky because of my autism, but people are like, well, you don't have to tell me that. We don't care.*

> *And how does he explain it? That's a good one. He will say that…my processing is different from yours because of my disability and my disability is autism.*

She believes that he was comfortable with his autistic identity, and would often self-disclose in many situations, including at workplaces. His co-workers understanding of his autism and their acceptance, contributes to his self-awareness and acceptance of himself. Annie, however, is cautious of her son's ease in disclosure. Her desire for him to limit his disclosure in certain situations is likely tied to the stigma associated with autism in society and workplaces, and be a reason for potential future employers to not hire him. She sees TJ's natural athleticism and volunteer work with Special Olympics as a boost to his self-esteem, but also broader advocacy and activism work in the disability community. More on self-advocacy can be found in the following section.

For each of the families, their young adult child experienced multiple job opportunities during their adolescent and young adult years. All required and received a high level of support from their families to find and maintain employment and because of that help, all five have now been continuously employed for one or more years. Parents also described how important work was to their children's self-esteem and the role of the workplace in helping their children feel a sense of belonging at work.

After the pandemic shuttered the first restaurant/entertainment complex, Ross worked a series of jobs, including one at a restaurant, where he did not like the way he was treated by other employees. Trish said,

> *I think that the thing that needs to happen with these guys is that they feel successful in what they're doing…. Ross could feel like they were being demeaning to him and it's not the way he wanted to feel.*

So, while where he worked mattered less to him and his mother, Ross wanted to feel appreciated at whatever job he was in. Trish continued,

> *I mean they're just so good to him; it's his kind of thing. It's the arcade. But the people, there again, the supervisors are very appreciative of him. And so Ross goes over and above to try to help other departments and do different things. Like today he went in early.*

Ellie used the term ‘identity’ on two occasions in our conversation. When speaking about Mark’s transition experiences and being exposed to the world of work, she says,

> *He loves to work, absolutely loves that. He finds identity with his work, and it gives him a sense of purpose.*

Later in our conversation, I learned that Mark’s dad also works at the same medical device company. I also learn that Mark has only held part-time roles before, averaging about 15 hours per week. This full-time job, combined with the company’s mission, which they tell employees is saving lives, and the fact that he works at the same company as his dad, reinforces Mark’s identity with his work. Ellie says, “this is his identity right now”.

Young adults in this study had varying levels of understanding how their autism affected their ability to participate in the world of work. Autistic self-awareness was highlighted negatively in work-situations, such as during interviews or interacting with colleagues. Parents stories also revealed consistent values in all young adults related to working a job, achieving financial independence, and finding self-worth through working.

Support and Advocacy

Advocacy can be defined as “speaking or acting on behalf of another person” that “can encompass a broad range of activities” (Lee et al., 2022, p.) and was a central theme in conversations with all five parents.

As their children got older, parents' advocacy took different forms but the most common was evident through advocacy for access to social services, education, and sourcing the skills needed for independence. In high school, it became apparent that a different type of advocacy was needed, one that focused on the role of transition, independent living, and employment outcomes.

> *I was actually more focused on transition earlier on than school was. I started looking at things when he was in ninth grade.* (Lee, parent of Milo)
> *Both of his older brother and his younger sister were college bound, and we really wanted him to have that same opportunity if he wanted it. And he did. So I just started digging into what kind of programs were available.* (Lee, parent of Milo)

Lee's awareness of her son's needs continued to change to fit the age and situation.

> *Having that driver's license and being independent in that way was very important to him. So we championed that as much as we could.*

Lee's expectations of Milo's future were influenced by her experience with her niece with Down's Syndrome, who is now in her forties, and has lived with her brother and sister-in-law her entire life. She believed that her niece could have had a more "full" life and so, in her own's son case, she emphasized that "*having him transition and not live with me for the rest of my life was really important*." These examples also illustrate the shift in type of advocacy from finding and implementing therapies and dealing with special education and IEPs as their children were younger, to finding and supporting the skills and activities that would help lead to an independent life.

At each stage of advocacy development, the assertiveness described by parents was a learned process, as parents realized that schools would do the minimum required to adhere to the IEP. For instance, Ellie self-describes as a “tiger mama” when it became apparent that schools would find ways to minimize the support they provided. She also describes that she had to learn to be a tiger-mama the hard way.

> *Early on I don't think I really asked for anything. I think they just said we're going to do job exploration, and I was okay with that.*

From that point on, she learned the importance of getting everything in writing and emphasized this as something that parents who were just starting to work with schools should learn.

The parent’s role in finding opportunities for their children to work and advocacy for the supports needed for them to be successful in their jobs was consistently seen in all five cases. Following high school graduation, parents helped their children identify and obtain jobs. Ellie notes that Mark has “*never gotten a job on his own*” and has required help finding and applying for all the jobs he has held. In Milo’s case, Lee remembers leveraging the relationship she had with the owner of a local bar and grill to help secure Milo’s first job. Advocacy did not stop there, as more support was needed, and Lee was able to advocate for Milo to have an on-site job coach.

> *He was in his first job at the local Bar and Grill. The owner called me and said, hey, you know, it's working, but it's not working out the greatest. I think Milo could use some extra help, like learning what to do. And we're too busy, I just don't have time for that. So I said, well, would you be open to a job coach coming in? And she said, absolutely. So then, we contracted with Functional Industries…. and he had a job coach from there that coached him through the job at the Bar and Grill.*

Andre remembers the circumstances leading to Jesse securing an interview with his current company. Two situations coalesced that led to that opportunity:

> *We connected him with the Minnesota Workforce Center. And then our daughter who is the middle child, she was dating a young man at that time whose father was CFO for a parts manufacturing company, a robotic parts manufacturing company. And, between the two, he got an interview at this robotics parts manufacturing company called [name of company].*

Similarly, Trish recalls her husband initiating the process to get Ross his first job in high school.

> *My husband was the cause of the first one which was great. He went by the [restaurant/entertainment complex] at one point, which is the arcades and all those kinds of things. And they were looking for help and so Ross started there.*

All parents mention the importance of staying connected in some way with the current employer. In Jesse's case, Andre arranged a 'Take your dad to work day', where he spent a day at Jesse's workplace, getting to know his team, and getting a feel for the work culture. He mentions that there always seems to be a need to help with something related to work.

> *He's talked about going to HR before, because that's more about, you know, processes. I help him because I know financial planning. I help him out with a lot of the benefit type of stuff. Just understanding how it applies to his life.*

Now that Milo is a full-time employee without the support of MindShift, Lee worries who will keep her updated on Milo's progress and worries that he will miss things, putting his employment status into jeopardy.

> *Since he's been transitioned to a full-time employee, I'm not entirely sure, honestly. I feel a little bit lost. I know it's part of cutting the apron strings and letting him be independent and responsible for himself. But as a parent, that's really hard. I do have his boss's email and we have been figuring out benefits and things like that. And his boss just emailed me. We missed a step in something that I have to do, but it's fine.*

Parent support and advocacy are important themes that are revealed through parent narratives and are consistent with what is found in literature related to the role of parents of autistic children. According to parents, advocacy is an ongoing process that often starts before diagnosis and is particularly intense in children's early years as the foundation for special education is being laid. Parents expressed feelings of uncertainty as their children aged and their advocacy efforts must transform to reflect their children's achievement of independence. While advocacy ebbs and flows at various points in later years, there is never really a point where it can be turned 'off'.

Self-advocacy was also found to be a focus of what parents wanted to share about their child's experiences. Self-advocacy refers to the ability to speak up for oneself and was demonstrated by young adults speaking up in various situations. In my conversation with Lee, I learned that she sees her son as a "pretty mellow" person who "can roll with change pretty well". She contrasted this character trait as being "unlike the stereotypical person with autism". However, I then learned that it was important for her son Milo to be liked by others. His easy-going nature had led him to participate in activities he did not want to, and consequently, he became unhappy. Milo's did not want to be perceived as having the typical traits associated with autism, such as rigidity to change and lack of concern about other people's feelings. Lee explained how his self-awareness of his autism and self-advocacy intersect,

> *And obviously he knows he has it. I think he doesn't necessarily recognize the degree of how it affects him. You know in ways like, for a while, not advocating for himself.*

Parent interviews also document the growth of self-advocacy behaviors in their children. The development of Milo's advocacy skills was the result of multiple factors. He attended all his IEP meetings, and towards high school graduation, was asked to lead the meetings himself. His mother notes that this was a tall order for any young person, let alone one with a disability, but it seemed to plant the seed to help learn to speak up for himself. Over time, Milo has become more confident advocating for his needs without feeling that if he said no to requests, it would make people stop liking him.

> *But he's gotten so much better at advocating for himself. I mean, he'll do that with us if we've had a family gathering and then there's something else going on, he might say, I have had enough family, <laugh> now I want my downtime. And his roommate TJ is very active and likes to go and to do a lot of things. And TJs always wanting Milo to go here, go there. And Milo was saying, you know, I just finally had to tell TJ I just needed to chill out <laugh>. So I think that's great because several years ago, Milo would've just gone along and been unhappy about it and now he feels confident that people are still going to like him.*

Andre was clearly proud of Jesse's new role of department supervisor and how he has started to use the advocacy he witnessed directed toward him for most of his life, towards his staff.

> *One of his coworkers that now reports to him was saying something about work and it was a concern that she had. I can't remember what the subject matter was, but Jesse said something to the fact of, well, Mary or whatever her name was, I can't remember. Well, you need to advocate for yourself.*

TJ uses his love of Special Olympics to advocate for the inclusion of adaptive sports through presentations at high schools and has also been interviewed on TV many times on behalf of Special Olympics. She shared a recent interaction she had with TJ after he had an encounter with a young boy with Down's Syndrome and his father at a local restaurant.

> *Hey, I got to show you something. I'm part of Special Olympics, A lot of my friends have Down syndrome like your son and they're great. He showed him*

> *pictures of them, and I said, were they okay with that? He goes, oh yeah, they thought that was great. I told him that I have autism, I'm like, oh, okay.*

Self-advocacy was a skill that all young people expressed in different ways, but was related to the advocacy efforts that children witnessed through their parents' actions. In some cases, self-advocacy was related to autism self-awareness, in both positive and negative ways.

Outside advocacy mentioned by parents refers to agencies such as The Arc Minnesota, Vocational Rehabilitation, a Division of the Minnesota Department of Employment and Economic Development, and companies such as MindShift, an employment agency that work to place autistic adults in competitively paid jobs. Outside advocates can serve different purposes. In the case of Arc, Trish asserts that they have always been their "family's advocate" and the person-centered planning services they provided when the boys were younger help them determine what therapies and support they might need at different stages of their life.

> *Arc was always our advocate. We always had advocates to help us through some of our meetings and what not, which I always thought was really helpful.*

Trish said they often refer back to the person-planning centered planning process with While Ellie and Mark did not have a "*positive experience*" with Vocational Rehab, the job exploration experiences they provided may have helped Mark develop a deeper understanding of the skills needed to get and maintain a job. After high school, Mark attended MICC for three years, which not only helped with his acceptance of his autism, but where he learned life skills, and had a year-long internship at Best Buy's corporate office.

Ellie credits the work of MindShift with finding the job at the medical device company and providing on-going support to Mark with an on-site job coach. The job coach was present for the first year of his employment and checks back in as needed. Mark's co-occurring mental health diagnoses have often made communication a challenge, making it difficult for others to interpret some of the things he says, or taking them out of context. Ellie brought up a recent situation at work where they needed MindShift's advocacy.

> *And so that's where I've been really happy to have MindShift involved. In fact, I had to reach out to [MindShift job coach] because of something my son told me last week, like he said somebody brought up sexual harassment to him. And that's not my son. He wouldn't do that, but I could see that if he said something, it could be interpreted that way. So that was a big red flag. And I called her [job coach] right away.*

Lee credits both Vocational Rehabilitation and MindShift with creating positive work outcomes for Milo. His vocational rehabilitation case manager attended his high school IEP meetings and demonstrated a level of care shown that was absent in interactions described by other parents. These interactions were also instrumental in helping expand Milo's ability to self-advocate. MindShift's advocacy at the medical device company resulted in an intervention and movement to a different department when the first job did not work out.

> *He was in a different position at the [medical device company]. And that just wasn't working out so well because he was in the lab, and there were so many steps to follow and he just was getting overwhelmed, I think, with the number of steps. So then, Mind Shift was able to secure him a different job within the same company.*

Another important finding related to the role of workplace culture in creating a sense of inclusivity and belonging at work. When Andre visited Jesse at his job, he was struck by how nice everyone was and the nice things they had to say about his son. And he said,

> *And it just can't be because Dad's here.*

Trish stressed the importance of feeling appreciated and valued at any workplace.

> *I mean they're just so good to him; it's his kind of thing. It's the arcade. But the people, there again, the supervisors are very appreciative of him. And so then Ross goes over and above to try to help other departments and do different things. Like today he went in early.*

Advocacy does encompass efforts made by specialized employment agencies like MindShift and their job coaches who provide in-real-time support, advocacy, and feedback at work. It also includes advocacy in the form of person-centered planning and approaching future planning from a strengths-based perspective.

Theme 2: Inadequacy of Comprehensive Transition Programs (CTP)

This theme relates to parent challenges with navigating the special education system, planning and implementing transition activities, and creating a tailored transition plan for their children that maximizes successful outcomes, including CIE.

From these interviews, most parents report minimal involvement with and relevance of school-provided transition planning to their child's future. Some even believed that school-provided transition planning would be detrimental to their child's progress, and they would regress, rather than learn new skills. When asked about any employment related goals in their child's IEP, parents responses were minimal, and any job experiences through the IEP were related to jobs such as putting the tops on bottles or folding towels at a local hotel. While these experiences were not always positive, four out of five parents affirmed the importance of some type of post-high school education in helping launch their child's journey into independence. The exception to pursuing post-school education was Trish, and this may have due to Hugo and Ross' different support needs, and because sending Ross to a post-secondary program like MICC or Bethel's BUILD program would have involved separating the boys again.

Andre seemed pleased with the services Jesse received through their school district, describing them as "wonderful". Starting with early childhood education, a bus would pick Jesse up and take him to his therapies and classes. During elementary through high school, his IEP provided modifications where more support was needed, but because Jesse was fixated upon becoming a railroad conductor, they chose to skip post-secondary transition offered by the school, in lieu of the community college he attended. It was at this point that Andre realized that the consistent communication provided by high school was not typical of the supports provided in college. Andre remembers when Jesse was in his final class at the community college, and he needed to complete an internship or experience. Andre reached out to the instructor himself and was told that Jesse could just write a paper instead.

> *So he did this paper, I can't remember, it was something about the various different rail companies here in the Twin Cities. And he completed it, and got his railroad conductor certificate. So maybe that's why I'm not remembering the details, but he didn't get any support and I got concerned at that point.*

Ellie's experience with her school district was always overshadowed by Mark's inability to accept his autism and his rejection of supports. Even so, she describes elementary school as "pretty decent" in regard to supports, but middle and high schools as "horrible because of the hormones and the lack of support". Since Mark rejected his autism diagnosis, she knew that the school provided transition programming would not be an option for him, as he never saw himself as having a disability. She believed it would be more harmful than helpful to Mark if she forced him to complete the additional three years of transition planning. She credits MICC with helping Mark accept his autism and start to build work-related skills through internships. In wrapping up her story, Ellie shared some advice for other parents regarding how to work with school districts. She offers,

> *That's the biggest thing I can say. I always learned that when they tell me, no, we don't do that, I'd say, please put it in writing. When they say, well, we won't, then I'm like, well see. That tells me you're supposed to do it. You're just not going to do it because of money.*

Both Milo and TJ attended Bethel University's BUILD program after high school. Lee remembers that the decision to find an alternative experience for Milo was a result of several factors: not wanting to attend the school transition program because he was "higher functioning" than the students there and "would have outgrown the program pretty quickly and might have been bored"; that he wanted an independent living experience similar to his siblings; and finally, Lee wanted a program that would expose Milo to jobs with a higher level of skill than the ones that school transition planning offered.

Like Ellie and Lee, Annie explored the possibility of school- provided transition planning for TJ, and rejected it. After graduation, TJ attended a community college, but only lasted one semester as he did not receive any supports. After that, he stayed home for a few years, till Annie learned about the BUILD program, and TJ was accepted. She believes that the independence he fostered through the skills learned in the program was a positive factor in managing the depression he experienced after high school.

The ability of parents in this study to choose to create their own transition plan for their children can be viewed as a rejection of school district offered CTP. Creating a tailored plan requires a vision that there were programs with 'better fit' for their children's current abilities and the potential for them to learn new skills.

Theme 3: Lack of Knowledge and Limited Access to Resources

This theme is related to parents' ability to access knowledge and resources to maximize their child's development through multiple developmental stages. As their children continued to progress through the special education system and approach graduation, parents ability to access post-secondary education and resources tied to successful employment are also tied to parents' own socioeconomic status and level of education.

For Ellie and Lee, their ability to understand the importance of early intervention helped them look beyond the services offered through early childhood education and seek out alternative interventions, such as ABA therapy, to deliver at home.

> *We had early intervention. We did early childhood special ed through the school district. And then I also did an at-home ABA therapy program that averaged about probably 30 hours a week for about two years, almost three years.* (Lee, parent of Milo).

For many of the parents interviewed, the process of knowing where to look for resources beyond what was provided at school to further their children's path to independence was tied to parents' own educational attainment. Ellie says,

> *It's what breaks my heart, you know. Like you and I, clearly, we have education, and we know how to ask questions, you know, so we get lucky. We find resources sometimes, but I feel so sorry for people who don't know how to ask questions and don't know where to look.*

Once parents gained the knowledge and skills to advocate effectively, they felt more confident in their ability to build on those advocacy efforts. Ellie felt as if Mark's school district was being less than forthright about goals that needed to be in his IEP and that the school needed to provide resources to implement. To hone her advocacy efforts, she worked with the Minnesota Disability Law Center "because I like to know my rights and what I can and cannot do". She also says, "*I also have some other connections in the community just because, you know, autism mom you kind of meet people*" as a way to describe the constant networking that parents of autistic children undertake in order to find resources that may be beneficial to their children.

What was left unsaid in these interviews is that the ability to even know to look for a resource outside those provided by the school takes education and awareness on the part of the parent. For parents with the financial resources, it allowed them to reject the standard transition offered by the school district and create their own transition plan, individualized to the needs of their child.

> *I was actually more focused on transition earlier on than school was. I started looking at things when he was in ninth grade. I just knew both of his older brother and his younger sister were college bound, and we really wanted him to have that same opportunity if he wanted it. And he did. And so I just started digging into what kind of programs were available. Most of them at that time were out on the East Coast, and so that was a little bit daunting to me. So much of it is very cost-prohibitive, which I feel really bad about. I mean, Milo's dad and I do okay financially, so for us, we would've been able to swing it without help from a waiver.*

Here, the waiver that Lee is referring to is the Consumer Directed Community Supports waiver, available through the Minnesota Department of Human Services. This waiver gives eligible recipients, often disability populations, access to funds that allow them to create a tailored plan of supports based on their individual needs. Funds can be used for special therapies, pay staff, and training to help you achieve certain goals. In Milo's case, the waiver may have covered the tuition to attend a private-pay post-secondary program like Bethel BUILD.

The above quote brings together several themes identified in this study: the ability to create a tailored transition plan, education on the part of the parent to seek other resources, and the financial resources to pay for it without state or county help. Additionally, even though Milo's parents divorced when he was around 12, they continued to work together to ensure that Milo would receive any support he was entitled to through the county to build skills related to work.

> *When he was probably in ninth grade or tenth grade, I knew work was going to come around the corner and I knew they had work support. I lived in [Greater MN] County, so we used my address, thinking that he might get better services in [Greater MN] County than he would have in Hennepin.*

When there is a diagnosis of autism, many two-parent families make the decision that one parent will stay home with the child in order to coordinate therapies and the other parent will work. This was the case in Andre's story, where he worked full-time and Sonja, Jesse's mom, stayed home in order to prioritize Jesse's care. This reflects both a financial privilege to be able to support a family on a single income, as well as a time privilege as the time spent traveling and coordinating appointments in the health care system and education system was often challenging and time-consuming.

> *That was a period when I was building my practice and she and I had to decide on different roles. So she ran our house. It was a great system for us because she was able to do that while I just worked. And then, I just showed up at home and*

> *said, "What do you want me to do? Where are we going? When?" And it worked out great.*

Knowledge and resources represent an important asset that parents in this study possessed that may not be typical of other parents with autistic children. Since all young adults in this study came from two-parent households (either intact or parents divorced and remarried), this too represented a resource that allowed one parent to spend a significant amount of time cultivating knowledge of programs beyond those offered at school that would help advance the goal of independence and CIE for their children.

Theme 4: Dogged Determination

What I found most compelling in listening to parents' stories was the nature of their ongoing role in their children's lives that helped their children believe in their own abilities and contributed to their social and emotional development. This type of continued engagement on the part of the parents and positive goal achievement from their children can be described as 'dogged determination' that developed over time. Two examples from parents' stories provide more clarity regarding this development. Andre shared that the specialist who diagnosed Jesse told him that he would never be able to button his shirt. When I offered my view that it was a long way from that stark, almost cruel diagnosis to Jesse being head of his own department at work, Andre became visibly emotional, acknowledging the effort that was involved in making that happen. Similarly, when Annie was told that a group home was the best place for her son, she refused to accept that as TJ's future, dedicating "*a lot of blood, sweat, tears went in with him, but he's doing really good*". TJ's achievements with Special Olympics, living independently, and working a full-time job are sources of pride for Annie.

Rather than focusing on the disabling aspects of autism, parents focused instead on how they could amplify their child's strengths and find supports for areas of need. For each young person, their autism self-awareness meant an understanding that independence was a much harder to reach goal. As one example, when Jesse realized at 20 that being a train conductor was not within his reach and he needed to pivot to another career, that was a compromise to his self-identified aspirations. Ironically, while Jesse demonstrated maturity in this realization and subsequent decision, Andre expressed his disappointment.

> *He was being a better adult than I was about that, because I had this little box check marked and thinking, yep. Jesse is doing things that he likes off in his railroad career. Great. Happy dad. And then he made a better decision for his life, I think, than I was leaning towards.*

For Jesse, pivoting to new job interests meant that both he and Andre had to refine how success could be achieved. After moving on from his rail interviews, he found a temporary employment agency which Andre described as "horrible". The lack of structure with those roles also exacerbated Jesse's anxiety and his need for routine. Just as Jesse reached a new level of anxiety, his parents made a connection with the Minnesota Workforce center, as well as leveraged the relationship their daughter's boyfriend had with the CEO of the parts manufacturing company.

There appears to be a cyclical element in learning new skills and arriving at the current point of stability and independence. Parents' expectations and conviction in their child's abilities positively affected their child's belief in themselves, and led to goal achievement. The child's achievement then spurred greater resource seeking and advocacy on the part of the parents. Each time parents raised the bar on expectations and their child was able to achieve that new goal, it created a new cycle of parental expectation and positive goal achievement on the part of the child. For parents, this meant for example, while independence was a goal, it had to be approached strategically, breaking down each goal into its' smaller, separate components. Each of these smaller components revealed areas of strength, or areas where greater supports were needed.

Through each narrative, I learned about the various jobs each young adult held. Each successive job taught different skills, and helped the young adult. What makes this significant is considering each opportunity as a way to learn new skills, balancing this with any co-occurring diagnosis and their parents define and redefine their goals for themselves. was a contributing factor in building resilience and stamina as they navigated longer work hours and balanced work with independent living skills.

Summary

This chapter provided an in-depth look at the case study data following five parent interviews. Data analysis grouped major findings into the categories of the role and expectations of parents, knowledge and resources, rejection of school supported CTP, and the theme of dogged determination, which refers to the ability to persevere despite numerous challenges. What stood out through analysis of the data is no surprise to anyone who has worked with autistic populations; i.e., what worked for one child, did not work for another. However, what was consistently reported was that all parents were ambivalent about the role of transition services before and after high school in helping their child learn new skills and achieve independence. Parents also continue to play the role of advocates, though that advocacy may have changed in type and intensity over time. All parents also shared the amount of effort it took to achieve current stability for their child. The following chapter will discuss the overall findings of this study and present strategies for parents who have not yet experienced the transitions process, as well as strategies for agencies such as Vocational Rehab to consider as they seek to support young autistic adults in their journey to competitive, integrated employment.

Chapter Six

My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style.

Maya Angelou

Discussion

The purpose of this qualitative multiple case study was to explore how parents of autistic children helped them navigate post-school transition into adulthood and obtain competitive, integrated employment (CIE). The high unemployment and underemployment rates in adult autistic populations highlight the importance of understanding factors that support their transition from school into adulthood and obtaining CIE. Research suggests that the role of parents is instrumental in achieving successful adult outcomes, including employment. The intention of this study is to understand the strategies parents used, the challenges they faced, and their advocacy efforts that have resulted in their children successfully obtaining CIE.

Following the overview of the study is a discussion of the major themes identified from interviews that are supported in the literature, with strategies used by parents that positively impact the attainment of CIE. Findings aligned expectancy value theory and broaden-and-build theory. Expectancy value theory operationalized through parent expectations expressed directly or indirectly, influenced their children’s beliefs about their own capabilities and subsequently resulted in the child’s achievement. Broaden-and-build theory operationalized through positive parent emotions and increased parent expectations led to a positive gain cycle. This positive 'gain cycle' is one mechanism to understand how the other closely linked themes of parent knowledge and resources, advocacy, and an increased autism self-awareness in their young adult result in positive adult outcomes, including CIE. In this final chapter, I discuss these findings, implications for HRD and professionals that support autistic young adults in post-school transition, and end with recommendations for parents, future research, and a final reflection.

Study Overview

For all students, the transition from high-school to adulthood is fraught with challenges and anxiety. Autistic students are no exception and for many, parents are their primary support in navigating school systems, complementary therapies, and social services. The path after high school is less structured, and parents provide on-going support to assist with transition into adulthood. Unfortunately, comprehensive transition planning (CTP) and the involvement of key adult service agencies to support post high school plans offered by school districts does not offer the type of tailored supports that help lead to achieving adult outcomes, including independence, social connectivity, and competitive integrated employment. This is evidenced, in part, by the high employment and underemployment rates in autistic populations. Some families, however, have found a way to navigate a post-school transition and help their children obtain CIE.

This study utilized a qualitative case study approach to address the research problem with the question, 'How do parents of autistic children help them navigate a post-school transition into adulthood and obtain CIE?'. Five parents of autistic young adults participated in 60-90 minutes interviews, and narrated their stories, which contributed to the findings presented here. Parents offered candid responses to interview questions related to their experiences with transition planning, their child's desire for independence in adulthood, and the types of structures and supports that helped their children obtain and maintain CIE. After transcription and during the data analysis process, I reviewed codes from each interview, and grouped major findings into four major themes and sub-themes:

- Theme 1: The role of parents
- Theme 2: Inadequacy of Comprehensive Transition Planning (CTP)
- Theme 3: Lack of Knowledge and Limited Access to Resources
- Theme 4: Dogged determination

Presentation of the Findings

The data analysis focused on identifying themes that were relevant to the central research question and sub-questions. The theories I used to support this study were Wigfield and Eccles' expectancy value theory (2000), and Fredrickson's broaden-and-build theory (2001). Codes were assigned to keywords and phrases within the participant transcripts, which led to the identification of the themes in cross-case analysis. Trustworthiness of findings was achieved in part, through member checking of transcripts and thematic analysis. An important finding that spanned all five stories and undergirds each theme relates to the heterogeneity of autism, and how each young adult's different strengths, interests, and behaviors necessitated a wide variety of strategies on behalf of their parents to help obtain CIE.

Theme 1: The Role of Parents

All five parents cared deeply about their young adult's future and played a central role that was critical to the success of their child's development and educational journeys. Four out of five parents revealed that early diagnosis was the impetus to start intensive therapies such as

ABA and early childhood intervention classes. Parents were also highly involved in IEP development and goal setting throughout high school and stressed the importance of being aware of their children's needs. Thoughts about their child's future, and work especially, remained prominent in anticipating and planning for next steps. Based on their child's needs and any co-occurring mental health diagnosis, each step after high school was carefully considered, in order to achieve a step-by-step process to CIE and independence. It was apparent from all five interviews that parents remain a trusted source for information and decision making. This is consistent with research suggesting that for autistic youth, the role of parents is central to the successful transition from school to adulthood (Wong et al., 2021; Burke et al., 2019; Burke et al., 2021), with family context (household income, parental support and expectations, parent education) influencing parent engagement in preparatory activities which contribute to positive adult outcomes (Holmes et al., 2018; Kirby et al., 2016).

The Influence of Parental Expectations

The diagnosis of autism changed several parents' expectations for their children's futures. For the parents in this study, these early diagnoses, combined with a lack of awareness of how to parent an autistic child, and pressure to alter future expectations, represent an emotionally difficult time. However, these parents showed an enormous amount of resiliency, and quickly pivoted to find suitable education and therapies to support their child's needs. These findings highlight their rejection of the view that their child is "abnormal" or "flawed", but must now be reconciled with new expectations of what might be achievable (Goldsmith & Kelley, 2018). This is consistent with literature that indicates that early diagnosis of autism disrupts the expectations of parenting and how new parents see themselves. This may be based on their own childhoods and experiences of parenting that are available through many public sources (McDonald, 2014).

Interviews indicated that as parents gained more confidence in navigating the educational needs of their child, their expectations for their child's future started to change. Changing expectations influenced the type of activities parents engaged in, with a focus on enhancing various adult outcomes for their children. Literature suggests that these activities or behaviors on the part of parents are "learned or internalized by adolescents" and influence their children's own beliefs, attitudes, and behaviors (Doren et al., 2012, p. 8). Parents' expectations for success may also be tied to particular autistic strengths, such as the ability to hyperfocus on topics of interest, and they look for ways to leverage these autistic strengths into a job. Parents also expressed more positivity for their child's future when contextualized around these interests and strengths, with the hope that these interests and strengths would be useful to them in employment.

Success in out-of-school activities also plays a role in shaping parent expectations. As one example, four families participated in Special Olympics, and demonstrated high levels of achievements in their chosen sport. Participation in these activities enhanced their children's ability to improve socialization and expand their communication skills which are important life skills to nurture. This is consistent with literature that suggests that parents demonstrate more optimistic expectations of their child's future as a result of positive out-of-school activities (Kirby et al., 2020).

One key finding across all five stories was the importance of having a job in high school. Shattuck (2012) advised "The best predictor of getting a job after high school is getting a job in high school and there's no substitute for real-world experience" (p. 2). Literature suggests that parental expectations are a significant contributing factor in establishing positive outcomes related to employment for their autistic children (Kirby et al., 2020). Parents who are highly involved in their autistic child's transition planning process do so with the expectation that their child will be involved in a 'real job in the community for real pay and benefits' (Holmes et al, 2018; Kirby, 2016; Wehman et al., 2018). Similarly, Doren et al (2012) identified parent expectations of future paid employment as a significant longitudinal predictor of paid employment for youth with a range of disabilities.

The values of positivity and optimism for their children's future were expressed multiple times through the interview process. The ability of their children to work a full-time job and/or live independently was a source of pride for parents, as it demonstrated to them that their children were able to fulfill their expectations, as well as exceed the expectations of others (e.g., early childhood, diagnosing doctors). Nevertheless, the influence on parental expectations remains complex, as there appear to be opposing views between parents and children on the long-term sustainability of jobs. This is evidenced through imaginary events, for example, lay-off's in Jesse's case, or doubt that skills parents have taught their children are insufficient for success. Despite expressing hopefulness for their child's future, parents simultaneously offered considerations of issues that leave them with doubt, uncertainty, and concern for the future (Kirby et al., 2020). Similarly, Chen and colleagues (2019) studied parents' future expectations of their children aged 14-21 with a range of disabilities expressed an oscillation between their hopes, expectations, fears, and uncertainty. This fear of an uncertain future emphasizes that stability, an essential value for families that live with autism, is transient and not something to be counted on. These sentiments expressed by parents in this study may be grounded in the fear of their own mortality and role as their children's main source of support, and wanting to ensure their children would have the skills they needed to be independent, but also not be a burden on other family members.

Autism Self-Awareness

An important finding in this study is related to young adult's desire for independence, and finding a job, expressed through their parents' narratives. All five young adults demonstrated varied levels of autism self-awareness, which in turn impacted the amount and type of work they could do, as well as any support they needed to be successful in employment. Findings supported that a heightened autism self-awareness affected the type of work each young adult was engaged in, and a willingness to accept supports promoted success. One interesting finding mentioned by a few parents related to the concept of sensory overload resulting in autistic burnout or fatigue. While burnout is a widely studied HRD topic, when examined in the context of autistic, it refers to a debilitating condition caused by the "stress of masking and living in an unaccommodating neurotypical world" and can result in reduced participation in daily activities and possibly suicide ideation (Higgins et al., 2021, p. 2356). Advocacy as offered by outside organizations, such as MICC or Arc, or the on-the-job tailored support developed by job coaches trained to work with autistic populations, can aid in developing self-awareness of triggers and stressors and create strategies for how to mitigate autistic burnout.

Parents also described the importance of work to their children's self-esteem. Significant literature has demonstrated that the ability to work and earn an income can positively affect an individual's self-worth and self-esteem. Autistic individuals are no exception, with employment contributing to their transition goals of independence, as well as higher well-being, and higher quality of life (Hurley-Hanson et al., 2019). Self-esteem can also come from fulfilling aspirational goals created through parent expectations. Parents' expectations, even when not communicated directly, can have a positive effect on creating aspirational goals (Doren et al., Lindstrom, 2012).

Self-esteem was also increased through workplace culture, seeing one's work reflected in the organizational mission, or through nurturing relationships at work. Workplace cultures that demonstrate inclusivity and belonging help inspire a deeper sense of loyalty in autistic employees (Hurley-Hanson et al., 2019). However, not all workplaces demonstrate the level of care and inclusivity that is essential to autistic young adults being successful at work. Trish remembers prior work experience of Ross' at a restaurant, where the nature of the job in filling both drive-up and counter-service orders often resulted in the perception that he did not work fast enough. He told his mother that his co-workers would often make demeaning comments to him, and yet Ross had the sense that the comments were related more to his autistic characteristics than his performance on the job. His mother goes on to say, "and that's not how he wanted to feel at a job".

Support and Advocacy

Lee and colleagues (2022) define advocacy as "speaking or acting on behalf of another person or group of people and can encompass a broad range of activities, such as pursuing education, direct help, or system-level change" (p. 1002). Advocacy can also be described as speaking for those who cannot communicate their needs. Many autistic individuals especially remain vulnerable to exploitation and abuse even as adults, hence, advocacy helps protect their interests. Advocacy takes many forms and was a central theme in conversations with all five parents.

Findings indicated that parental advocacy straddled a balance of awareness of their children's strengths and abilities, with the need to find resources to support their areas of need. For parents of autistic children, advocacy often begins before diagnosis when they suspect that their child may not be reaching developmental milestones. This early work sets the foundation for what often becomes a lifetime of advocacy for their children. Parental advocacy can also be influenced through experiences with other parents in similar situations.

Interviews revealed that advocacy may change in intensity as their children mature and a level of independence is achieved. When support changes from a day-to-day effort to a less frequent need, advocacy changes accordingly. Smith-Young and colleagues (2022) add that parental advocacy is "a dynamic process that changes depending on the circumstances and needs" (p.1). Parental advocacy was also a factor that improved service access for their child in adulthood. In order to achieve successful adult outcomes, parents have to be the driving force behind seeking, gaining maintaining, and creating fit for their autistic child in the adult world (Lee et al., 2022; McDonald, 2014), as individuals with autistic may lack the resources or knowledge to find and secure employment (Hendricks & Wehman, 2009). There are numerous stories of parents of autistic children, especially mothers, who have transformed their advocacy into an activist role in an effort towards campaigning for change outside of their own families (McDonald, 2014). While this was not the case in this study, all parents demonstrated an enhanced advocacy role for their own children related to working in CIE, and advocating for the type of supports that would ensure their success at work.

Self-advocacy can be a difficult skill for autistic individuals to develop, especially in adolescence, and was evidenced in parents' stories. Parents remain their child's advocates by providing the guidance necessary to move from one developmental stage to another. Children can also become better advocates for themselves after observing their parents' advocacy efforts on their behalf. This adoption of self-advocacy runs parallel to the change in intensity of advocacy efforts that parents make on behalf of their children. As their children age and mature, parents shared how their children feel empowered to disclose their autism in various situations, which lessens the need for parents to speak up on their behalf. While a lesser finding, the promotion of autonomy, and the right to say no, as it relates to self-advocacy was also apparent in some cases. Leadbitter (2021) describes the principle of autonomy as fundamental to the development of self-advocacy and "creating the life one wants to lead" (p. 2).

All five parents had minimal experience in approaching and advocating for support from community service agencies such as Vocational Rehabilitation in their child's transition years. One parent reported a highly negative experience with Vocational Rehabilitation, whereas one parent described a good experience for her son using Vocational Rehabilitation. This parent also disclosed that her son had been diagnosed with an intellectual disability. Studies have shown that autistic youth with an intellectual disability often achieve better employment outcomes using employment services offered by Vocational Rehabilitation than those without an intellectual disability, or autistic with cognitive (dis)ability. McDonald (2014) adds that employment services designed to assist people with disabilities find work often do not necessarily meet the needs of clients on the autism spectrum without intellectual disability (McDonald, 2014).

A key finding was that a positive, supportive work environment, either through supervisor support or an inclusive work culture is a factor for success. Advocacy in the workplace occurred through a supervisor familiar with working and supporting autistic individuals, the parents connection to their child's supervisor or job coach at work, or the business model and long-term job coaching supports used by MindShift. Parents emphasized the importance of staying connected to supervisors or job coaches to directly communicate their children's support needs to them. Parents also relied on the advocacy of others to support their children at pivotal times, such as at annual IEP meetings, during person-centered planning, and through challenges at work. Services provided by organizations such as Arc and MindShift can act as a secondary source of strength to parents in situations where the parent may lack knowledge or is not always able to directly intervene.

Theme 2: Inadequacy of Comprehensive Transition Planning (CTP)

This research study started out with the assumption that comprehensive transition programs (CTPs) and the involvement of key adult social service agencies was the primary type of support used by parents. Findings revealed, however, that parents viewed CTP as inadequate in supporting achievement of adult outcomes, including CIE, and was used to a lesser degree or not at all. In fact, parents described CTP as primarily preparing students for low-skilled, low-wage jobs. Parent criticism of services offered as part of CTP is also related to the explorative nature of job experiences versus job placements. Some parents stated that the classes offered, and skills taught by some of their local CTPs, would lead to regression in communication and social skills, rather than an advancement or learning new skills. This implies that parents perceived the skills taught in those programs as rudimentary and not an improvement over their children's current adaptive functioning. While there are a range of abilities in individuals that attend these programs, parents interviewed in this study appeared to be most concerned about the involvement of their own children with those with greater support needs. Individuals with autism have often been grouped together in employment programs with others who have intellectual and developmental disabilities, and may not adequately meet their needs, interests, or strengths (Astous et al., 2014). Therefore, parents seek services that offer a better fit for their children's current level of skill, and help to increase adaptive functioning in adult settings.

During interviews, most parents referred to their children as "high functioning", a term used in the disability community and often even in research, to refer to those with lower support needs (Anderson et al., 2020; Kelly et al., 2018). Autism advocates believe that the terms high and low functioning are misleading, as even those considered "high functioning" have support needs that are not always obvious (Alvares et al., 2020). As one example, Annie remembers a pivotal moment after TJ graduated high school when TJ's dad and her were deciding on options for his post-secondary education. Rather than sending him to the school district CTP, they decided to send him to a nearby community college. Without the type of supports he received in school through his IEP, it was difficult for TJ to attend classes, and complete the work required for more than one semester.

Similarly, Andre remembers having to intervene with an instructor to help Jesse complete a required assignment in a class as part of his railroad conductor certificate program. He also recalls that Jesse did not have access to the type of supports provided through an IEP while he was attending the certificate program. While Jesse completed the program and earned the certificate, it was not without difficulty. IEPs end in 12th grade if parents and young adults choose to opt-out of the transition program offered by the school district. While there are often traditional supports available at many colleges and universities, they are often generic in nature, not autism specific, and do not offer a tailored level of support (McDonald, 2014; Nachman et al., 2021). While some institutions are beginning to implement Autism-Specific College Support Programs, which include services such as, tutoring services, peer mentors, social skills training, and a higher level of parent involvement, they are often cost-prohibitive for smaller institutions to implement (Nachman et al., 2021). Four parents in the study referred to their children as “smart/very smart” and/or “high functioning” and expressed a desire for them to attend college, and yet the range of academic and supportive accommodations required for them to succeed educationally, and transition to greater independence was not always possible through the traditional supports provided through college disability programs (VanBergeijk., et al., 2008).

Instead of defaulting to CTPs, parents sought a better educational fit that maximized acquiring adult skills for their children, which could be applied across different settings (McDonald, 2014). Bethel’s BUILD and MICC are examples of two programs that teach a combination of post-secondary life-skills and vocational training for adults with disabilities. McDonald (2014) describes these types of decisions as “seeking progressive fit” between the student and the institution to maximize their child’s educational potential (p. 72). Parents’ whose children attended these post-secondary institutions reported a high degree of satisfaction with the programming offered and believed their children were able to learn skills that contributed to independence and employment. In contrast, none of the parents interviewed believed that their CTP was able to offer the type of skills that would have aided in independence or the types of jobs that would be a good fit for their children.

The decisions made by these parents to reject the default and find alternative education for their children shows how such parents continually strategize solutions to gain, maintain, and create educational fit to maximize their children's educational potential (McDonald, 2014). These decisions are also tied to the types of resources available to families from higher socio-economic backgrounds. Take for example, the demographics found at the CTP in the Minneapolis school district, commonly referred to as Transitions Plus or TPlus. This program has a minority enrollment of 73%, with 68% of students from economically disadvantaged backgrounds (Student Accounting, Minneapolis Public Schools, 2021). In contrast, MICC and BUILD's high tuition serves as a barrier to access to students from lower socioeconomic backgrounds. MICC's program costs alone, at $46,240 for the 2022/2023 year are a prohibitive barrier to entry for many. The difference between the private transitions programs like MICC and BUILD, and CTPs, can also be seen in the quality of programming. MICC and BUILD offer a college-like experience with supported housing, the ability to learn skills related to independent living and employment through an on-campus living experience, and on-site internships, reducing the need for parents to coordinate supports. CTPs offered by some school districts are often constrained by funding, rarely contain an immersive living experience, and often rely on parents to piece together supports from various service organizations.

Theme 3: Lack of Knowledge and Limited Access to Resources

Two things I have learned as the parent of an autistic child are, 1) there is no blueprint for this work, and 2) the amount of time and effort to support the raising of an autistic child can be likened to a full-time job. This finding was also echoed in the stories of all five parents. In the search for therapies, services, and individualized education that prepared their children for adulthood, parents constantly acquired or brokered services (Burke et al., 2019). Acquiring services necessitates that parents research new information, identify and evaluate treatments, learn how to navigate social services, and make connections with larger communities for support and advocacy. Acquiring services is also tied to financial resources, as parents of autistic children often seek experimental or complementary therapies for their children that are not covered through insurance or government waivers. In this study, several parents mentioned their ability to pay for services without the help of insurance or waivers.

Through their narratives, parents indicated the on-going, often relentless nature of staying informed and educated. Knowledge is also foundational to advocacy, as in order to successfully advocate for their child's needs, parents need to know enough about the adult disability system and its' many types of services, what their children may be eligible for, and alternatives that are available (Taylor & DaWalt, 2017). Smith-Young et al (2022) write, "parental advocacy is an ongoing and multifaceted communicative process that includes staying informed and educated" and is tied to acquiring knowledge about autism and resources related to the development of skills. During interviews, parents shared that the quest for knowledge and resources often began with securing the most appropriate educational environment for their children. Each subsequent action to secure the best resources led parents to a more positive perception of their own efficacy, and a more positive perception of their child (Fleischmann, 2004). This dynamic process of navigating knowledge and resources helped parents become increasingly savvy about which services might be best for their child.

As children aged through the special education system, the search for post-school knowledge and resources becomes heightened with the approach of "the cliff", the age often dreaded by parents of children with disabilities when they become ineligible for many services (Kirby, 2016). Parents in this study indicated that even their previous groundwork navigating the high school system and fragmented transition supports did not prepare them for what would happen after graduation. Unable to help their children in similar ways to high school, parents felt a sense of powerlessness. All parents reported that their children struggled to get and keep continuous full-time employment. These findings highlight that in spite of parents' constant search for resources, the lack of knowledge of available adult social services, including access and eligibility, remains a barrier to all families.

Research indicates that work experience is considered an essential step for some individuals on the autism spectrum in preparing them for more permanent paid work (McDonald, 2014; Shattuck, 2012). Parents often researched, leveraged contacts and resources for suitable workplaces, advocated for their children, and found ways to support them as they gained work experience. Parents interviewed did this at varying levels and was consistent with Kirby's findings (2020) demonstrating that parents ability to research and connect to resources are shown to promote successful transition to adulthood (Kirby et al., 2020). Both Mark and Milo were able to secure work during high school due to the resourcefulness of their parents and their parents' ability to engage the services of job coaches. Most importantly however, it demonstrates awareness that work experiences help build job related skills and are important steps to prepare for potential future work.

Knowledge is also a pre-requisite for parents to be thoughtful and informed advocates for their autistic children (Taylor et al., 2017). Knowledge of how to advocate for their children in order to maximize educational resources through an IEP or job coaching through Vocational

Rehabilitation was an important finding. For instance, Ellie, Mark's mother talked about her involvement with the Minnesota Disability Law Center, a resource offered by Legal Aid that provides free civil legal assistance to individuals with disabilities or their families, on legal issues related to their disabilities. Ellie referenced this resource in parallel with her self-description as a "tiger-mama", as she often sparred with educators at IEP/transition meetings to obtain services for Mark that he was entitled to, and that would help him be successful in school. This finding highlights that knowledge and advocacy often go hand-in-hand.

Parents' narratives emphasized the importance of always being aware of what was on the horizon for their children's lives – from high school to post-secondary education and beyond, seeking interests and activities to build social and communication skills, independent living skills, work experiences that build job-related skills – and the need for parents being the ones to create a step-wise approach to implement future activities. For instance, Annie described how she thought through multiple steps that would be involved with TJ being able to afford a car, many of which were tied to work. Annie is already thinking ahead about the future and the activities that would be needed to make that future a reality.

In this study, parents' ability to access knowledge and resources to maximize their child's development are tied to parent's own socio-economic status, level of education, and parental expectations. Through the information revealed in interviews, I identified the careers of parents as nursing, investment banking, and marketing professionals. Previous research on the influence of the family has shown that certain family characteristics, such as parental socioeconomic status, influence future aspirations, and early career choices (Kirby, 2016). Youth in economically stable families were also more likely to be exposed to a variety of career options, which influenced where they see themselves working in the future (Dean et al., 2021). For parents with professions that require post-secondary education (e.g. nursing), the types of jobs they see their children working in may be influenced by their own work, and thus influence the type of resources they seek to access. All but one parent mentioned their socio-economic status, which privileged them to be able to pay for therapies and tuition at programs like MICC and BUILD, without the help of government waivers and other assistance. Participation in these programs, in turn, contributed to positive adult outcomes such as increase in independent living skills, and exposure to internships which helped build job-related skills. The lack of easily accessible resources after high school makes enrollment in CTPs planning the default for many families from lower socio-economic backgrounds. Some of the jobs that these parents work at are likely also lower skills jobs. For these families, the type of jobs offered by Vocational Rehabilitation are likely similar in skill to what the parents themselves are employed in. In these case studies however, the higher income and resources available to families meant they could reject the default and create their own transition plan.

Theme 4: Dogged Determination

The period towards and after high school completion was often described by parents as chaotic and anxiety ridden. Some challenges seemed aligned to those of parents raising neurotypical children, such as obtaining part-time jobs in high school, or exploring post-secondary options. The difference for parents of autistic children is that these periods seem to be characterized by greater intensity. Anderson et al. (2020) reported that the 2-3 years after high school presented significant disruptions for many autistic individuals, and included job changes or loss, or movement among post-secondary educational settings to find the right fit. While there may be multiple ‘pain points’ related to changes for both parents and children, the difficulties related to autism can be greatest in adolescence and young adulthood. Upon high school completion or graduation, participation changes from the structure offered in a class setting to less structured participation in areas such as finding work, developing a social network, contributing to a household, and participating in a community (McDonald, 2014). The parents interviewed here all experienced a heightened level of anxiety as the stability of high school ended, as they struggled to marshal their resources, and find the next ‘thing’ for their child. It was clear that stability remained critical for both parents and young adults.

Perhaps one of the most striking similarities in the stories shared by all five parents can be seen in the period after high school, where exploration (related to education and employment) and seeking ‘goodness of fit’ intersect with perseverance and optimism. This ‘dogged determinination’ can be described in modern parlance as the ability to ‘keep it moving’. In their quest to find or create the best fit for the child post high-school, parents also mentioned their children’s interests and passions, trying to find ways to use that to their child’s advantage, and looking up possible careers based on those interests. In Jesse’s case, the need to pivot after realizing that a career in the rail industry was not going to work for him at the time, in-part because of his autism, could have led to prolonged depression. However, in a nod to his determination he registered with a temporary agency and worked a variety of part-time jobs, until the serendipitous meeting with his sister’s boyfriend led to an interview for a kit assembly technician. Interestingly, Andre remembers Jesse’s second childhood interest was playing with Legos, which kit assembly work resembles in some ways. All young adults in this study have encountered and overcome enormous challenges in order to get to their present stable state. This ability to overcome and to persevere in spite of challenges can be described as dogged determination.

Parental expectations and their child's achievement also play a role in conceptualizing dogged determination. Doren et al (2012) suggest that parents with higher expectations may also be parents who believe in their child's potential to achieve future outcomes. These expectations are associated with positive emotions and may look like parental support, encouragement, and opportunities to engage in activities that increase adolescent's own sense of capability. An increase in adolescent sense of capability is also associated with more positive social, emotional, and behavioral outcomes. High parental expectations then lead to yet more activities that strengthen their child's proactive behaviors and achieve transition goals. When parents observe that their child has exceeded their previous expectations, this leads to a reappraisal, and revision of expectations. If the child reaches or exceeds this new expectation, the cycle begins again. This type of positive feedback loop can be evidenced in Barbara Fredrickson's Broaden-and-build framework, which suggests that focusing on the positive aspects of parenting a child with a disability helps generate new thoughts and proposed actions in both parent and child. This gain cycle fosters new and enduring psychological, intellectual, and social resources in both parent and child. This dynamic interaction between parental expectations and their child's achievement suggests that they are mutually reinforcing. Holmes and colleagues (2018) suggest that that parent expectations and actions interact in a reciprocal manner over time, as parents incorporate information from their child's response to various actions into their expectations for the future, which in turn help them choose further activities they believe will be effective for achieving their child's goals. Kirby and colleagues (2020) note a similar finding; parents who hold higher expectations engage in transition preparation activities that promote opportunities for their child to develop skills to accomplish outcomes. Thus, dogged determination can be posited as a gain cycle that is observed in the relationship between parental expectations and its outcomes.

Implications for Human Resource Development (HRD) Professionals

HRD’s humanistic orientation is often at odds with the plethora of research generated that focuses on issues of importance to organizations; i.e., how to maximize employees’ learning through activities that support behavior change and lead to high performance (Kwon, 2020; Torraco & Lundgren, 2020). The organizational emphasis on high performance has the unfortunate effect of prioritizing ableism as essential and productive, and those with disabilities as deficient and unproductive (Kwon, 2020). Largely, discourses on disability are absent from the diversity, equity, and inclusion (DEI) conversations and plans that are dominant in many talent recruitment strategies (Procknow & Rocco, 2016; Torraco & Lundgren, 2020). Even when found in the literature, physical disabilities are dominant HRD research interests, with cognitive and neurodevelopmental disabilities all but invisible (Johnson et al., 2020; Torraco & Lundgren, 2020). In addition, HRD, as an essential part of organizational leadership, often focuses its’ efforts on issues of scalability. Unfortunately, tailored approaches are required for autistic employees to realize their strengths and be successful in the workplace (Austin & Pisano, 2017). Challenges related to the success of neurodiverse employees are “workplace challenges that HRD should be dealing with as part of its legitimization as a force for developmental good” (Farkas et al., 2020, p. 379).

Autism’s heterogeneity in presentation and array of supports needed can make it daunting to find an entry point for the HRD researcher and practitioner. However, the high unemployment and underemployment rates in autistic populations should serve as a call to action, and a constant reminder of what is at stake, for researchers, practitioners, schools, adult social service providers, and policy makers. Johnson and colleagues (2020) and Austin and Pisano (2017) offer a place to start in their papers. Since social and communication deficits are ASD characteristics common across a range of abilities and pose barriers to obtaining and retaining successful employment, they suggest new research should focus on hiring strategies and social skills development in the workplace.

Another workplace strategy that has been shown to promote success in job seeking and retention is the use of a trained job coach. A job coach that is experienced in supporting autistic employees can work one-to-one with them to develop tools and strategies to promote workplace success and provide advocacy as needed. Among the criticisms leveled against workforce development specialists and job coaches is that they tend to be generalists and lack specialized training to work effectively with autistic job seekers. While competencies for specialists working with autistic job seekers do exist, training and development varies across service agencies, as well as nuances involved with implementation of practices. The value of a trained job coach extends beyond the autistic employee. They can also provide guidance to employers and supervisors on the importance of job modification, clear job structures, and meaningful accommodations, thereby creating a supportive environment. Accordingly, much can be learned from employment specialists working with autistic seekers that already have high placement and retention rates; HRD is well positioned to facilitate programs that leverage the partnership between autistic job seekers and job coaches to promote, create, and sustain optimal workplace environments for a diverse workforce.

A workplace environmental accommodation that needs more research is related to the use of technology in competitive workplace settings to teach new tasks and improve job performance (Khalifa et al., 2020) for autistic employees. Autistic populations often display an affinity for technology; a strength that can be used to mitigate a variety of autistic-associated challenges in the workplace. As an example, smart devices (such as iPods or smart phones) can be pre-loaded with a suite of applications to serve as personal digital assistants and “provide task reminders, task lists, video-based task-sequencing prompts, behavioral self-management adaptations, direction-finding tools, and other supports” (Khalifa et al., 2020, p. 1326).

While very briefly mentioned by a parent in this study, disclosure related to protected statuses, such as gender or disability, can have detrimental effects at work, and result in stigma, isolation and exclusion, and stereotypes (Procknow & Rocco, 2016). Thus, the stigma associated with disability disclosure makes many autistic employees reluctant to share their diagnosis, which then limits the type of accommodations they are able to receive. Austin and Pisano’s (2017) Harvard Business review article offers considerations for employers seeking to tap into the huge talent pool represented by autistic employees. In order to combat the work preference stereotypes and stigma associated with autistic employees, they emphasize the importance of managers and supervisors in including individuals with autism in their teams and setting the right tone. Supportive supervisors and co-workers may also be able to provide natural job supports, a form of on-the-job supports. Natural supports also necessitate training and development to work and communicate effectively with autistic co-workers. As valuable members of organizational leadership teams, HRD practitioners can provide on-going training to support managers and supervisors in creating inclusive workplace cultures and reducing the stigma associated with disability disclosure.

Autism researchers have documented the many benefits of hiring autistic employees. These benefits include autistic-specific strengths such as “attention to detail, systematic information processing, strong memory, error detection, pattern recognition, systems thinking, and visualization” that result in increased productivity (Annabi & Locke, 2019, p. 502). In contrast, HRD and human resource management researchers focus on the impacts that hiring autistic employees has on corporate social responsibility and creating a high-quality brand that is synonymous with diversity. It is important to note that both of these efforts can exist together.

HRD scholars and practitioners also have an opportunity to contribute to the identity-first autism advocacy efforts that are gaining momentum. There are several ways to do this. HRD scholars can work closely with autism self-advocates using community based participatory research to dispel myths and perceptions around the presentation of autism (Farkas et al., 2020). They can also work at an organizational level to create a culture of inclusivity and reduce the stigma associated with disclosure. HRD practitioners can promote the development of autism affinity groups at work and together with managers and supervisors, encourage participation. As one final suggestion, Procknow and Rocco (2016) highlight the absence of HRD mentoring research in HRD. Mentorship as an employment strategy is often associated with career progression for employees without disabilities. Mentorship then, can have similar success for employees with disabilities through a “proper match-fit” (p. 392).

Implications for Professionals Supporting Students in the Transition from High School

Kohler and Field's taxonomy for transition planning (in, Chandroo et al., 2018) consists of five areas proven to increase post-school success. The five areas include student-focused planning, student development, interagency collaboration, family involvement, and program structure. In addition, post-secondary education is an important goal for many students with disabilities, and for autistic students, it has been associated with achieving successful adult outcomes. Obtaining post-secondary education involves successful transition planning in three broad areas: school, student, and parent related variables (Ruble et al, 2019). Parent factors such as expectations, parent education level, and parent involvement have been addressed in this paper. The findings of this study also suggest implications for professionals such as special education staff and adult social services agencies who support students in the transition process and are addressed below.

School/special education staff generally introduce IEP/transition planning between 14-16 years of age, or no later than 9th grade. In order to maximize skills development for autistic students, school districts should consider offering community-based education or job exploration as early as middle school. In Minneapolis, the Step-up! youth employment programs run during the summer months and present an ideal opportunity to engage youth in job exploration activities without interrupting school learning. Jobs before graduation help build work ready skills such as, navigating transportation and time-management skills, communicating with supervisors and co-workers, and learning expectations on the job. Community-based education can also provide training opportunities for self-care/independent living and social skills that help increase adaptive functioning, self-advocacy and self-determination skills (Taylor et al., 2019).

In IEP/transition planning, parents can be school staff's strongest partners and yet many families report feeling unsatisfied with the planning experience. Actively involving parents and students in the process helps foster deeper engagement with families. Deeper engagement with families builds trust, which better position school staff to encourage families to identify the things their children can do well and start thinking about transition planning as early as possible. One caveat to this, special education staff should be mindful that families from historically marginalized communities can continue to feel disenfranchised during the IEP process. Immigrant families and those from lower socioeconomic backgrounds may also struggle with navigating and reestablishing adult social services for their autistic children (Shogren & Plotner, 2012). School support staff can help by reducing the amount of jargon in an IEP and asking parents to invite another trusted adult to planning meetings. Research has found that post-school, parents realize that the transition plans offered to them were vague and not fully developed, and that this might have resulted in their young adult being less prepared for life after high school (Kim and Morningstar, 2020). Thus, measurable IEP goals should relate to positive outcomes in independent living (as appropriate), competitive integrated employment, and a social network. A well-structured IEP/transition plan should clearly services to be provided with expected goals, timelines, who will be responsible for implementing these services, as well as a plan for monitoring and following up on the implementation of activities. To help establish adult services, school and adult social service professionals should ensure that families have appropriate and adequate knowledge related to their child's transition. Collaboration with adult social services agencies is also critical and should indicate key contacts that parents can follow-up with (Roberts, 2010).

Research suggests that autistic students can and should be involved in their own planning. Chandroo et al (2018) state that student-focused planning helps autistic students identify their own interests, strengths, and areas for growth and build skills related to self-determination. Student involvement in IEP/transition planning can be demonstrated through the development of the following communication skills: introducing themselves, introducing IEP team members, state the purpose of the current meeting and recap prior goals, ask for feedback or ask questions if they did not understand, state support, and end the meeting by thanking everyone. While students may demonstrate a range of proficiency in completing these tasks, the goal is to start with small steps that build self-advocacy and self-determination skills.

Limitations

This study explored how parents of autistic children helped them navigate post-school transition and obtain competitive, integrated employment and should be interpreted with the following scope and limitations in mind. Special education services remain protected till age 21, so the scope of this study only included parents with children older than 21 years. The reason for this selection is that these parents likely had the most experience on the adult transitioning phenomenon. The qualitative nature of this study and the heterogeneity of autism poses a limitation to external validity. The results are also limited in that they don’t generalize beyond the parents included in the study. My sample was relatively small, and drew from a population that was white, well-educated, and well-resourced, with three parents connected to each other through a parent autism support group. Parents and children representing racially diverse populations and those from lower socio-economic strata were not represented in this study. Thus, parents who have the means to seek support and services beyond what is offered in schools may have different expectations for transition and beyond. Parents from lower socio-economic strata may also be less aware of, and may not have the same access to outside resources as parents from higher socio-economic strata. I relied on parents, in good faith, to provide honest and accurate information based on the questions that were asked. Questions were designed to focus on transition-activities related to employment, although it is highly likely that parents engaged in many other adult preparatory activities that benefited their children which were not shared during interviews.

Future Research

This study design used a purposive sampling approach and recruitment was limited to only parents. Parents that met eligibility criteria were also white, well-educated, and well-resourced. Since parents are likely the decision makers for many areas of their children's lives including adult preparatory activities, young adult voices were not included in this study. Youth perceptions for their future were considered indirectly through their parents' narratives. Four areas for future research are presented here that build on the work done in this study:

- A methodological consideration to improve future studies would be a focus group with parents together, separate interviews with autistic youth on their perspectives of employment and transition-support, and then, combined focus groups with parents and autistic youth. This would present opportunities for autistic youth to share their voices and increase opportunities for them to build self-advocacy skills. Having a matched parent and child focus group would also provide more consistent results and deep learning on the challenges and needs of both stakeholder groups (Lee et al., 2022).

- This study drew from a population that was white, well-educated, and well-resourced. Future studies should seek parents of youth from lower SES and racially diverse groups who have successfully transitioned to adulthood and obtained CIE to explore any differences in how they navigated a path with CIE. The ability of the parents in this study to realize the inadequacy of school-provided CPT and create their own transition plan for their child that maximized their potential is a privilege that may not be available to lower SES families.
- This study aimed to capture parent expectations and activities that helped the transition process for their autistic child. While research questions were designed to consider longitudinal aspects of this process, it is likely that parents engaged in other adult preparatory activities that were not captured through interview questions. A consideration for future research should encompass multiple important transition points from middle school to high school in order to understand how parents used information from IEPs and their child's progress in school, to arrive at the decision to seek other post-school education.
- One finding in interviews that could be expanded on in future research, is parent's hope for their children to have a normal life and what normal means to families. Young adults parented in this study were diagnosed as autistic between 1997 and 2003, well before identity-first approaches have reached their current visibility in research and media. Parents shared the critical nature of early therapies, such as applied behavioral analysis (ABA), in helping their child learn to communicate. However, autism self-advocates oppose these approaches as trying to pathologize the autism and separate it from the child

(Leadbitter et al., 2021), versus identity-first approaches that help nurture the whole person. Future research could consider how identity-first approaches to parenting autistic children shape expectations of parents and the actions they engage in.

Recommendations for Parents, Schools, and Other Stakeholders

Autism research is often focused on the needs of young children. When that focus is turned towards autistic adults, it produces extensive research on barriers facing autistic populations. One recommendation for schools and other stakeholders such as vocational rehabilitation and other adult service agencies, is to utilize a positive framework to focus on opportunities that increase participation in the workforce. For adult service agencies, focusing on tools such as job carving can help align autistic job seekers personal interests with needs of employers. Research has demonstrated that when employment opportunities match autistic job seekers self-identified strengths, interests, and needs, they are more successful with higher job retention and working more hours and days. In searching for promising therapies and resources that fit their children's needs, parents should be an important partner at the table with IEP/transition planning, Vocational Rehabilitation, and employers who are looking to create inclusive workplaces. In addition to person-centered planning, family-centered planning is a collaborative approach that acknowledges the constant and enduring role of the parent in their autistic child's life, and draws upon parents' expertise to enhance future outcomes.

Parents are an integral part of their autistic children's journey to adulthood, and yet parents from lower socio-economic strata often do not have the resources to develop effective transition strategies, and may not always able to participate fully in their child's transition journey due to competing priorities. Lower socio-economic status is also associated with lowered parent expectations. Parents with lower expectations have a limited view of their adolescent's capabilities and provide fewer opportunities to increase their child's sense of capability. Similarly, parents of minority students with disabilities are less likely than parents of non-minority parents to think that their children will be employed (Doren, et al., 2012).

While factors such as parental income and education are associated with positive outcomes for their autistic child, these are difficult to change. Doren et al (2012) assert however, that parent expectations are dynamic and should be a focus for intervention, and offer several high priority recommendations for schools and service providers. Schools and service providers can offer information to parents on accommodations or supports that will help their child achieve school and postschool outcomes, thereby bolstering both parent and child confidence. Simultaneously pairing this recommendation with best practices to effectively prepare autistic young adults with transferable work-related skills, such as navigating public transportation, being on time to work, communicating with colleagues and supervisors, etc., would relieve some of the burden from parents. Research also documents that early work experiences in high school are a predictor of future work, yet most autistic youth have no high school work experiences and no real-world experience to practice skills learned in a classroom setting. A future recommendation related to successful employment should be the inclusion of at least one real-world work experience in all autistic youth's IEP/transition plan.

As their children age through the special education system and approach the need for adult services, a recommendation that focuses on the rights of autistic young adults, and how their parents can effectively advocate for them through their transition-to-adulthood would be helpful for all parents. One feature that could make this type of training highly effective is to create peer support groups that are made up of a mix of families from high and lower socio-economic status. This would give lower SES families the opportunity to learn first-hand, from well-resourced families on how they navigated systems and structures to obtain positive outcomes for their child.

The final recommendation reflects the need to hear stories from families who support their autistic family members, especially those from lower SES. Stories from families across all economic strata, however, can offer key insights into the multiple, intersecting systems that impact employment for young adults with autistic. Best practices within and across these systems should be disseminated to stakeholders, such as special education school personnel, policy makers who make decisions that fund disability programs and services, and to employers that are looking to create inclusive workplaces.

Final Reflections

This study described how the role of parent, through parent expectations and advocacy for their child’s needs, a tailored transition plan that emphasizes “goodness of fit” (Holmes et al., 2018; McDonald, 2014), and ‘dogged determination’ demonstrated by parent and child helped navigate a largely unstructured path post-school for autistic young adults to achieve positive outcomes, including CIE. The unspoken element of privilege undergirded parents’ advocacy efforts and was a factor in creating successful outcomes for their autistic child. For lower-income families with autistic children however, parents’ competing priorities and inability to access resources can be a barrier to parental advocacy efforts.

As someone in a doctoral degree program, I recognize my own privilege related to education and how that translates to an ability to access and advocate for resources that are a better fit for my son's unique needs. I also consider my particular field, Human Resource Development, and its' early objectives of providing employment and broader opportunities for individuals who are "unutilized and underutilized" (Johnson et al, 2020). While part of these objectives have been addressed through DEI conversations, disability, and especially intellectual or cognitive disability as part of DEI, have not been addressed well in HRD. With an 85% unemployment/underemployment rate in autistic populations, HRD needs alternative interventions to deal with an issue of this magnitude. My unique positionality as a parent **and** HRD scholar/practitioner lends itself well to promoting multidisciplinary research that engages parents of autistic children with workforce development agencies and other social service providers to inform the development of tailored services and develop competencies for agency staff to work with autistic job seekers. It also gives me the opportunity to ask how HRD can serve as agents of change to include intellectual and cognitive disabilities as part of DEI conversations, thereby facilitating improved work outcomes for ASD job seekers.

This study adds to the body of literature on how parent expectations play a role in predicting positive employment outcomes for autistic populations. It also reinforces the interconnectedness of knowledge/resources and advocacy with parent level of education and socio-economic status. As one of the newer generations of parents who have benefited from amendments to special education, we expect that our children will live and work in the community. The historical, political, and economic times we are living in make transition from educational to adult services significant, but still difficult to navigate. As the parent of an autistic young adult, I want a future for my son that allows him to explore his interests within a supported job, and where his autism is not seen as a deficit. With training and support, autistic populations can and should work in competitive, integrated employment.

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Appendix A

Semi-structured interview questions:

1. Tell me about your son/daughter with autism.
    a. Prompt: interests, work or volunteer experiences, mental health challenges (no diagnosis required)
2. What transition goals did you have for them?
    a. When did transition planning begin? Prompt: It usually begins in 9th or 10th grade?
    b. Who was involved in transition planning?
3. What were their transition goals related to achieving CIE?
    a. Who supported them in achieving these goals?
    b. Did you use any community-based services, such as VR?
    c. What did success look like?
4. What challenges did you encounter with preparing your child for CIE?
    a. How did you address these challenges, i.e. problem solve?
5. Tell me a little about the work they are doing now.
    a. What do they like most about it?
    b. Is the work full-time? Part-time?
6. Who supports them on the job?
    a. Who do they talk to if they need help?
    b. Do they have a friend at work?
7. What advice would you give another parent who is preparing for transition planning with their autistic child?

a. What would you have done differently in transition planning?

Appendix B

Email Templates

Email 1 (Sent to common clinician who will then share it with potential study participants)

From: silv0100@umn.edu

To: *Clinician email address*

Subject: Interest in a research study about parents who helped their autistic child's process in achieving competitive, integrated employment.

Hello, *Clinician name*,

Thank you for being willing to share this email with parents you think might be a good fit for my study. I have included my contact information in the email, so if parents have an interest in participating, they can contact me directly.

Best,

Cassie

[*Message to be shared*]

Hello,

My name is Cassandra (Cassie) Silveira. I am a doctoral student at the University of Minnesota, Twin Cities and I am conducting a study with parents of autistic children who have gone through transition planning. We have a common clinician, [*Clinician's name*], who offered to share this email with parents who might meet the criteria to participate in this study. Inclusion criteria are being the parent of an individual with a formal autism diagnosis who has already gone through transition planning, and currently is, or has been employed in a job with competitive wages. If this is you, I would like to hear about your experiences as you helped your child through this process, and in achieving competitive, integrated employment. This research is important to me and other parents for several reasons. I am also the parent of a young adult autistic son and understand the importance of receiving support from parents with similar experiences. I also believe it is important to share what I am learning with other parents who have not yet experienced the transition process or might be struggling with it currently.

If you are interested in speaking with me, please contact me directly and I can provide more details about the study. I can be reached by email at silv0100@umn.edu or on my mobile at (612) 578-2683.

Thank you,

Cassie Silveira

Email 2 (Sent from interviewed parent to other parents in their network)

From: *Parent email address*

To: *Other email addresses*

Subject: Interest in a research study about parents who helped their autistic child's process in achieving competitive, integrated employment.

Hello,

Thank you for being willing to share this email with parents you think might be a good fit for my study. I have included my contact information in the email, so if parents have an interest in participating, they can contact me directly.

Best,

Cassie

[*Message to be shared*]

Hello,

My name is Cassandra (Cassie) Silveira. I am a doctoral student at the University of Minnesota, Twin Cities and I am conducting a study with parents of autistic children who have gone through transition planning. [*Parent name*] recently participated in an interview with me and offered to share this email with parents in their network who might meet the criteria to participate in this study. Inclusion criteria are being the parent of an individual with a formal autism diagnosis who has already gone through transition planning, and currently is, or has been employed in a job with competitive wages. If this is you, I would like to hear about your experiences as you helped your child through this process, and in achieving competitive, integrated employment. This research is important to me and other parents for several reasons. I am also the parent of a young adult autistic son and understand the importance of receiving support from parents with similar experiences. I also believe it is important to share what I am learning with other parents who have not yet experienced the transition process or might be struggling with it currently.

If you are interested in speaking with me, please contact me directly and I can provide more details about the study. I can be reached by email at silv0100@umn.edu or on my mobile at (612) 578-2683.

Thank you,

Cassie Silveira