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Parent Perceptions of the Transition Programs Completed by Their Adult Children with Autism Spectrum Disorder

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Parent Perceptions of the Transition Programs Completed by Their Adult Children

with Autism Spectrum Disorder

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Concordia University – Portland

College of Education

Dissertation submitted to the Faculty of the College of Education

in Partial Fulfillment of the requirements for the degree of

Doctor of Education in

Transformational Leadership

Christopher Maddox, Ph.D., Faculty Chair Dissertation Committee

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Abstract

The lifelong effects of Autism Spectrum Disorder (ASD) impact the living, employment, and social aspects for individuals with the diagnosis and their families. In this study, I sought to determine parent perspectives of school transition programs completed by their adult children with ASD. Guided by the theoretical framework from Bronfenbrenner, Freire, and Mezirow, my purpose was to identify transition practices with which parents were satisfied and dissatisfied, as well as to seek their input about improving transition programming. With the unemployment rate for individuals with ASD reported by the Department of Labor as 80%, improvement of outcomes would reduce the burden on society and families. Although there had been research about best practices in transition programs, very little information existed about outcomes. In addition, parents, who are the primary caregivers for their children with disabilities, provide insights leading to better transition programming. In this phenomenological study, 12 parents of adult children with ASD completed a survey for demographic information and then, subpopulations of the participants joined interviews and a focus group. Data were collected using Creswell's and Moustakas' method of coding, horizontalization, reduction, and clustering around themes from the words of the participants. Although parents were satisfied with their level of involvement in transition planning, they were dissatisfied with unrealistic goals and the limited knowledge base of district personnel about transition options. Parent participants strongly encouraged development of social skills programs, more individualized programs, community connections, and expanding transition to begin when children are younger and end when they are older. The results of this study may inform both parents and professionals to create more individualized programs that meet the needs of each student with ASD.

Keywords: Autism Spectrum Disorder, Asperger Syndrome, high school transition

Dedication

This dissertation is dedicated first, to my parents. My mother who told me as I cried each day of kindergarten, "After this year, you only have 16 more years of school." I guess I fooled you! And my father who worked every day of his life and truly did walk to work through the snow then asked only, "How much money do you need for school?" Thank you both for instilling in me a love of learning and a dedication to hard work. I miss you both.

Second, I dedicate this dissertation to my husband, my Buddy, who provided financial as well as emotional support throughout all of my post graduate studies. Thank you for listening to all of it and still being there. Now it is our time.

I would also like to dedicate this to my support team: my brother, Joseph; sister-in-law, Janice; and sister, Clairanne, who provided technical, practical, and emotional support.

Next, I dedicate this to my son, Brendan, who although he fought it, proofread everything presented to him, and did a fantastic job. You continue to provide strength to this family.

Perhaps the most important dedication is to my son, Dylan, who is the inspiration for all of my efforts. You are my hero.

Finally, I dedicate this work to all of the families touched by Autism Spectrum Disorder that they may be helped in some small way by the information contained here. Never give up.

Acknowledgements

I would like to thank my family for their support and love through this entire process. I would

also like to thank my dissertation committee: Dr. Christopher Maddox, Dr. Julia Britt, and Dr.

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my heartfelt appreciation to the parents who shared their unique, personal experiences with me.

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Chapter 1: Introduction

Autism Spectrum Disorder is a developmental disability that affects an estimated 1 in 68 individuals born each year (CDC, 2016). Roux et al. (2013) estimated that the number of individuals with Autism Spectrum Disorder (ASD) who graduate from high school each year is about 50,000. As the employment rate for these individuals was reported by Autism Speaks at below 20%, the strain on families is a concern (U.S. Department of Labor Statistics, 2016). To combat this issue, schools have developed transition programs which consist of planned activities and instruction designed to prepare individuals for life beyond school. The purpose of this study was to explore how parents of adults with ASD describe their experiences of the transition program which their children completed.

Within Chapter 1, I introduce the background of ASD and transition as well as the problems associated with both. The purpose of the research, as well as the research questions, is discussed. An overview of the conceptual framework and the nature of the study are also specified. After a summary of the methodology, a list of terms relevant to ASD is defined. The chapter concludes with a discussion of assumptions, the scope and delimitations as well as the significance of the topic.

Statement of the Problem

Although refereed research relating to best practices in transition from school to life for individuals with ASD was available, there were very few studies that discussed how the programs have led to positive outcomes as measured by successful employment after school. Little was known about the perceptions of parents and caregivers regarding the programs and outcomes. Authors of refereed research documented best practices in transition programming but did not document positive outcomes. The data related to employment as a measure of success of transition

of individuals with ASD indicated unemployment rates of approximately 80%. The problem was the quality of life defined as sustained employment and independence had not improved for adults with ASD who have completed the transition process.

Purpose of the Study

The purpose of this phenomenological study was to describe the experience of the transition process from the perspective of the parents or primary caregivers of individuals with ASD. Although there was refereed literature about best practices in school transition, there was a lack of research into the experience through the eyes of the parents. Information about the outcomes for individuals with ASD was also absent. Through the study of parental transition experiences, it was possible to determine commonalities which lead to better outcomes and which can be used to improve transition programming.

Research Questions

The research questions for this study were:

1. What are the lived experiences of parents and caregivers of individuals with ASD who have completed a transition program from school to post-school?

2. With what aspects of school programs were parents satisfied?

3. With what aspects of school programs were parents dissatisfied?

4. What resources are needed for transition programs to be successful?

Conceptual Framework

The current, refereed literature, as well as Bronfenbrenner's (1979) ecological model of human development, Freire's (1970) critical education theory, and Mezirow's (1991) adult transformational learning theory grounded this study. The ecological model of Bronfenbrenner takes into account the myriad of relationships which people encounter over the course of a lifetime

and how those relationships help to shape and create the individual. This concept is a big part of transition in that there are many individuals who must come together to support the learning needs of the individual with ASD along with their future, post-school needs (Rowe et al., 2015; Shogren & Plotner, 2012; Test, Fowler et al., 2009; Test, Mazzotti et al., 2009).

Parents and primary caregivers are part of this support team for their children with ASD and acquire a knowledge base throughout the process as well as a wide range of experiences (Hurlbutt & Chalmers, 2004; Spann, Kohler, & Soenksen, 2003; Wehman et al., 2014). Many authors (Barnhill, 2007; Chen, Sung, & Pi, 2015; Farley et al., 2009; Spann, Kohler, & Soenksen, 2003; Test, Fowler et al., 2009; Wehman et al., 2014) referred to success in transition being reliant on the involvement and support of the family and changes in the views of individuals.

Connections were found between the concepts in current, refereed literature and Bronfenbrenner's (1979) ecological model of human development as well as the adult educational concepts of Freire (1970) and Mezirow (1991). These ideas supported the value of parent perceptions about the process of transition and outcomes by encouraging the building of helpful relationships and advocating for the unique views of families and changes in current thinking. The views of the three theorists: Bronfenbrenner, Freire, and Mezirow focused on understanding the perspective, status, and support systems of individuals to improve their outcomes. Phenomenology provided an appropriate method to define and explain the unique experiences of parents in this process of transition.

Nature of the Study

The rationale for selection of phenomenology as the approach to this study was my desire to access the unique experiences of parents and caregivers of individuals with ASD and to describe their feelings, thoughts, and mindset as they experienced the phenomenon of transition (Burke

Johnson & Christensen, 2014). The individual occurrence of the phenomenon was interpreted by the parent or caregiver who experienced it based upon a unique world view (Merriam & Tisdell, 2016). Thus, in this phenomenological study, I described how the participants have experienced the phenomenon. As Creswell (2013) described, my ultimate goal was to provide for the reader a description that helps them to understand what the experience was like for the individual involved in the phenomenon.

Summarization of the Methodology

The phenomenological research method identified the unique experiences of parents and caregivers (Merriam & Tisdell, 2016). Initial contact was made with possible participants through ▆▆▆▆▆▆ and ▆▆▆▆▆▆. When participants contacted me to express interest, I answered questions and assigned them to an interview or focus group. Participants signed consent agreements prior to commencement of the study.

Data was collected through a Qualtrics online survey, interviews, and a focus group. The interview and focus group questions were researcher-created based upon the research question and conceptual framework. Memoing and note taking was completed during the interviews and focus group. Transcriptions were completed within 48 hours of the interview or focus group.

The data was analyzed following the suggestions of Creswell (2013) and Moustakas (1994) beginning with horizontalization. The next step consisted of reduction and elimination to remove unrelated ideas. Then, information was clustered into associated meaning units. From the meaning units, textual descriptions describing the experiences were written for each individual interviewee and focus group, followed by structural descriptions explaining how the phenomenon was experienced. The final step was to

compare the individual experiences to arrive at the essence of the experience of transition from the parent and caregiver perspective.

Definitions

There are a number of terms which are associated with Autism Spectrum Disorder as well as educational transition program that required definitions:

Asperger Syndrome: This term is defined as the formerly separate disorder characterized by social and communication deficits without the repetitive behaviors associated with ASD (American Psychiatric Association, 2000).

Autism Spectrum Disorder (ASD): This term is defined as a disorder characterized by persistent deficits in social interactions and communication combined with the presence of repetitive behaviors that appear as the infant is developing and cause difficulty in social, occupational, and other aspects of life (American Psychiatric Association, 2013).

Evidence-based Practices (EBPs): This term is defined as educational practices that have been deemed effective through quality research (Test, 2012).

IEP (Individualized Education Program): This term is defined as a written plan for individuals identified with disabilities which require special education programs that identifies present levels of functioning, measurable annual goals and objectives, and the specific activities and services that will be used to achieve the goals (IDEA, 2004).

Intellectual Disability: This term is defined as a disorder that begins between birth and age 18 which is characterized by deficits in intellectual and adaptive functioning (American Psychiatric Association, 2013).

Lived experiences: This term is defined as the essence of the occurrence of the phenomenon under examination (Creswell, 2013).

National Longitudinal Transition Study 2 (NLTS2): This term is defined as the study funded by the U.S. Department of Education to collect long term data on high school and post high school experiences of a national sample of students representing the 12 federal disability classification categories defined by Individuals with Disabilities Education Act (Shogren & Plotner, 2012).

PDD-NOS: (Pervasive Developmental Disability – Not Otherwise Specified: This term is defined as the formerly separate disorder from ASD that is characterized by communication and social deficits without the associated repetitive behaviors (American Psychiatric Association, 2000).

Transition: This term is defined as a coordinated set of activities for a child with a disability that—

(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and

(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation. (IDEA, 2004)

Transition Programs: This term is defined as activities designed by a coordinated team of professionals for children with disabilities beginning at age 16 to achieve improved academics and functioning as they progress from school to post school (Shogren & Plotner, 2012).

Assumptions

There were certain assumptions which I had to make to enter into this phenomenological study. First, it was assumed that the parent or caregiver participated in the process of transition by attending meetings and communicating with the transition team including the student. A second assumption was that the volunteers for the study would be able to provide honest responses about their experiences either through the interview or focus group. I also assumed that parents' memories about the topic had remained fresh over the time since their children had participated in school transition. Participants' concerns about anonymity were addressed by providing pseudonyms and using initials for references to their children. To eliminate researcher bias toward themes, the words of the participants were used to create the final themes which answered the research questions.

Scope and Delimitations

The scope of this study was limited to parents of adult individuals with high functioning ASD. Although transition programming is required for all individuals identified with disabilities that have an Individualized Education Program (IEP), this study examined parent experiences of the phenomenon for individuals with ASD only. Another boundary of the study was the use of parent perspectives rather than direct observations of the process which was not considered due to the length of time required for such a study: two to five years. Many studies of individuals with other disabilities and more severely affected ASD cases were excluded from this

phenomenological study to focus on only the individuals without intellectual disabilities whose skills closely resemble nondisabled peers.

I reported the experiences and perceptions of several people to find a common meaning rather than just reporting the experiences of a single individual as in narrative research (Creswell, 2013). I did not search for a theory to explain the phenomenon as seen in grounded theory research (Creswell, 2013). Although individuals involved in transition programs may be seen as a culture-sharing group, ethnographic research would require a commitment of time which I was not able to meet. The nature of the case study with the focus on a bounded system did not fit the phenomenon that I was hoping to discover (Creswell, 2013). I did not report the experience of transition from the perspective of the students. There are several studies that have taken this perspective (Farley et al., 2009; Fox, 2011; Gerhardt & Lainer, 2011); however, little was known about the experiences of transition from the parent and family standpoint.

Limitations

This phenomenological study was limited by the recollections of the participants. The unique experiences of the participants were completed already; therefore, the impact of time on memory may have had an effect on the responses to questions. According to Creswell (2013) the qualitative research process is emergent; it is always changing to use the best methods to obtain the information. I used a self-designed list of interview and focus group questions intended to elicit information to answer the primary research question.

One limiting factor which could affect a study is the concept of reflexivity, or as Creswell (2013) explained, the author must convey their own personal relationship in the study. As the parent of an adult child with Level 1 ASD who has completed the transition process, I acknowledge a perspective on this topic. Although I have had these experiences, through the

process of bracketing and member checks, I kept my feelings in check and reported the experiences of the participants only.

Background and Significance of the Study

Transition programs are required for all individuals with Individualized Education Plans (IEP) in the United States once the age of 16 is attained (IDEA, 2004). The essential purpose of the plan is to provide appropriate instruction, supports, and services to the individuals with disabilities to assist them in moving from the school to post-school world successfully (IDEA, 2004). The literature reviewed in Chapter 2 provided a description of practices that are considered to be optimal for preparing individuals for life beyond school (Hendricks & Wehman, 2009; Rusch, Hughes, Agan, Marin, & Johnson, 2009; Test, Fowler, et al., 2009; Test, Mazzotti et al., 2009). Few studies existed that described outcomes of the implementation of these practices (Barnhill, 2007; Blackorby & Wagner, 1996; Farley et al., 2009; Shogren & Plotner, 2012; Taylor, Henninger, & Mailick, 2015; Wehman et al., 2014).

An estimated 50,000 individuals with ASD conclude high school services each year (Roux, Shattuck, Rast, Rava, & Anderson, 2015). The costs associated with the lifespan of one person with Autism Spectrum Disorder (ASD) without Intellectual Disability (ID) is approximately $1.4 million including costs of education, transition, and adult services like housing, healthcare, and public assistance (Roux et al., 2015). The unemployment rate of individuals with any disabilities was 11.1% compared with nondisabled peers' rate of 4.9% as reported by the United States Department of Labor (2016). It should be noted that any employment, including part-time, is included within that figure of 11.1%. The results of this study provide information about outcomes which may assist in creating stronger transition programs that support successful full-time employment and life choices for individuals with ASD.

Summary

I began Chapter 1 with an introduction to Autism Spectrum Disorder followed by a background of the disability. The problem statement explaining the lack of improvement of status of adults with ASD led to the primary purpose of this phenomenological study which was to describe the experience of transition from the perspective of parents or primary caregivers of individuals with ASD. As the nature of transition programs involves a wide variety of relationships built to support the progress of the individuals with ASD, Bronfenbrenner's (1979) ecological theory was discussed with regard to this phenomenon. The conceptual framework was encapsulated with Freire's (1970) critical education theory as well as Mezirow's (1991) transformational education theory which both described the critical changes in world views which must take place for progress to be made.

Chapter 1 continued with the rationale for the selection of phenomenology which describes how participants have experienced a phenomenon which has already been completed. The summary of the methodology which was based on Creswell's (2013) and Moustakas' (1994) suggestions preceded important definitions that apply to the topic of school transition. Assumptions, Scope and Delimitations, and Limitations explained the boundaries and obstacles to the study. Finally, the economic, educational, and social significance of the study was summarized.

In Chapter 2, I begin with background on Autism Spectrum Disorder. The purpose of the study is reviewed along with the literature search strategy. I describe the theoretical framework that supports an emphasis on the parent perspectives of transition programs. The literature review synthesizes the relevant research concerning school transition, ASD, and available programs.

Chapter 2: Literature Review

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that restricts the social interactions and communicative abilities of individuals with the diagnosis (American Psychiatric Association, 2013). Parents and caregivers are a good source of information about their adult children who leave school; they know the experiences, successes, and obstacles which affect individuals with ASD in post-school life. The input of the parent or caregiver may be helpful in exploring the problems that have a lasting effect on families and individuals with ASD because they have a unique vantage point. Many individuals with ASD are underemployed after leaving school as a result of deficits in communication and social skills (Test, Fowler et al., 2009). Roux et al. (2013) identified approximately 20% of the individuals with ASD in their analysis of National Longitudinal Transition Study 2 data, who were employed at the time of their study; while Shattuck et al. (2012) found that youth with ASD had a high risk of nonparticipation in either education or employment after high school.

The purpose of this study was to describe the experience of transition from the perspective of parents or primary caregivers of individuals with ASD. Although refereed research was available regarding the nature of school transition and best practices, there was a dearth of information about outcomes. Although school districts must complete follow up surveys with students who have graduated, difficulty accessing former students can hamper collection of data. The problem is the status has not improved for adults with ASD who have completed the transition process.

Chapter 2 begins with a discussion of the literature search strategy. Within Chapter 2, I describe the Conceptual Framework based upon the work of Paulo Freire (2000), Jack Mezirow (1991), and Leo Bronfenbrenner (1979) and their connection to transition programs. I also discuss

the nature of Autism Spectrum Disorders and present the foundations of transition programming as well as specific evidence-based activities which have been identified as best practices for individuals with ASD.

The transition program for individuals with ASD includes direct instruction as well as assistance from a variety of specialists including the special education teacher, guidance counselor, behavior therapist, school psychologist, vocational rehabilitation specialist, parents, and community representatives. These relationships and the progression of possible interventions identified through the research including student focused planning, development of employment skills, life skills and academics were presented. The data suggested that individuals with ASD are employed at an almost reciprocal rate to their non-disabled peers according to current employment data (U.S. Department of Labor Statistics, 2016). Best practices should achieve successful outcomes.

Literature Search Strategy

I accessed the Concordia University library to search three databases: ERIC, JSTORE, and Academic One. These databases were chosen due to the wide range of educational data available. In addition, Google Scholar was accessed to search for books and articles which contained information about ASD, transition, and theorists. The initial search of *ASD, high school transition,* and *Asperger's Syndrome* yielded 392 peer reviewed articles. After reviewing the abstracts, 25 articles were printed, read, and annotated. Those which were excluded included references to disabilities other than ASD or those which were conducted prior to 2011. After conferring with a Concordia University Research Librarian, other search terms were added to the initial group including: *career development, evidence-based practices, parent perceptions, post-school outcomes, and special education programs*. The search was limited to peer-reviewed articles

which referred to Autism Spectrum Disorders and Autism Spectrum Disorders with or without Intellectual Disability in conjunction with transition. A total of 78 articles were identified. After the initial articles were selected, it was also necessary to access the website and research library of the Centers for Disease Control (CDC) to identify particular statistics pertaining to ASD and to elucidate specific information. Authors such as Test, Mazzotti, Roux, Shattuck, Carter, Taylor, Seltzer, and Wehman repeatedly appeared in searches for this study.

Conceptual Framework

The bases of this phenomenological study were the theories of Urie Bronfenbrenner (1979), Paulo Freire (2000), and Jack Mezirow (1991). Bronfenbrenner's theory of ecology stated that individuals are surrounded by many zones of influence. Freire's critical education theory focused on learning through mutual respect and student-led curriculum to achieve freedom from oppression. Mezirow's transformational theory relied on critical reflection which enables adult learners to grow.

The transition of young adults with ASD to post-secondary education or employment occurs through the collaboration of many individuals: the student and parents, as well as school and community professionals (Test, Fowler et al., 2009). Transition is a time of change in placement, experiences, and supports for young adults with ASD (Wehman et al., 2014b). Urie Bronfenbrenner was a developmental psychologist who recognized that there are many relationships which help to shape people as they develop (Aubrey & Riley, 2016). Born in Russia, Bronfenbrenner moved to the United States when he was 6 years old. Bronfenbrenner received an undergraduate degree from Cornell University where he later spent his career as a professor and researcher; Bronfenbrenner was the inventor of human ecology, the interdisciplinary study of humans and their natural, social, and created environments – as well as the main force behind the

creation of the national Head Start Program in 1965, a federal child development program for preschoolers and their families (Lang, 2005).

In 1979, Bronfenbrenner published his *Ecological Theory of Human Development* which described the rings of interaction around individuals. Bronfenbrenner's theory describes the constantly changing interactions between a person and other people, the immediate environment, and multiple settings; the ecological model contains four zones or types of relationships, which overlap and fit together while individuals move from one zone to another and back again many times over the course of life.

The four zones have at their center the microsystem which encompasses the one-on-one interactions between individuals and the immediate surroundings. In this setting, individuals are involved in particular roles, for example, daughter. The next zone, the mesosystem, can be seen as a larger system which contains many microsystems as individuals progress through life (Bronfenbrenner, 1979). For the parent of a young adult who is transitioning to life beyond school, this level could include the family, school, businesses, vocational rehabilitation programs, among others that may be included at different stages of the life cycle. In the exosystem zone, the mesosystem expands to include other aspects of individuals' environments that have an impact on life though not immediately connected (Bronfenbrenner, 1979). In transition, these structures could include school programs, government resources such as Vocational Rehabilitation services, and community businesses. The final zone, the macrosystem, incorporates mores of society as well as laws (Bronfenbrenner, 1979). The macrosystem in this model is what controls the types of acceptable transition programs which can be created consistent with the culture and customs of the society. Bronfenbrenner's Ecological Model of Human Development provides a way to analyze relationships that occur in the life of a person.

As individuals with ASD enter the post-school world, they encounter many obstacles to full participation in employment (Shattuck, Narendorf et al., 2012). Individuals with ASD have a disproportional rate of unemployment when compared with other disability groups and the general population (Shattuck, Narendorf et al., 2012). Paulo Freire, a Brazilian educator and literacy reformer, stressed a radical view of education where students and teachers take part in a dialogue to identify topics of importance to create change in the world (Freire, 1970/2000). Freire grew up in a middle class family; yet, he did experience poverty and hunger in his native Brazil during the depression. He learned how society and economics can influence education (Horton & Freire, 1990). Freire earned his PhD from the University of Recife based on his work developing adult literacy programs with workers and peasants in Brazil (Horton & Freire, 1990). He spent most of his early years working to increase literacy in his home country of Brazil. Freire's teaching methods, which involved a common language and mutual respect between the learner and the teacher, were accepted and practiced throughout the country. After a coup d'état in 1964, Freire's methods were seen as subversive and revolutionary (Horton & Freire, 1990). He was imprisoned for several months and then exiled. He continued to work on his critical education theory in exile and worked in many poor areas around the world especially in South America and Africa (Horton & Freire, 1990).

Freire's (2000) critical education theory focused on understanding the life and position of the individual learners in order to determine what they are ready to learn. In Freire's approach, as explained in his 1970 *Pedagogy of the Oppressed*, the teacher spends time with the community to discover the words and topics most used, and then the teacher and the students can create a curriculum that the individuals want to learn (Freire, 1970/2000). The teachers and the students learn through a reciprocal process; therefore, the teachers are not the conferrer of the knowledge

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that they deem worthy but rather a catalyst to help the learner discover their world. Through the examination of factors which restrain particular groups from growing and succeeding, Freire's concept of pedagogy of the oppressed explains that through education, the oppressed can overcome the limiting situation. Critical education theory examines the political, social, and cultural factors of a society that determine why some groups do not have power and then works to make change (Freire, 1970/2000).

Three factors were central to Freire's critical education theory: dialogue, praxis, and conscientization (Freire, 1970/2000). The dialogue takes place between the teacher and the students to determine the cultural, economic, and political reality of the students so a curriculum may be created from the wants and needs of the learners (Freire, 1970/2000). The learners critically reflect on their limiting situation and goals and then create the means to achieve those goals. According to Freire, praxis is achieved by taking action against oppression – or the things that are limiting achievement. Instead of accepting what is given, praxis leads to a deeper understanding based on a constantly changing reality which is achieved through conscientization, a search for problems in the society that can be addressed (Freire, 1970/2000). This process allows individuals to realize their situation and take steps to change.

Jack Mezirow was a social scientist who earned his doctorate in adult education (Levine, 2014). He is most well known for his perspective transformation theory which promotes discourse in problem solving (Mezirow, 1991). Transformational theory in part developed out of critical theory but includes an examination of other perspectives and identification of the unique worldviews of individuals that obscure good decision making and learning (Mezirow, 1991). Transformative learning as described by Mezirow is a process whereby changes are made in the way individuals view the world or something in it by altering presuppositions. Mezirow's theory

is based on concepts contained in critical theory where social and historical assumptions restrain development and advancement as well as a broad range of other concepts in fields of philosophy, psychology, sociology, linguistics, religion and education. Mezirow explained in *Transformative Dimensions of Adult Learning* (1991) how he used ideas from others yet created his own theory. The experiences of individuals create their worldviews. For adults to make meaning they must examine ideas taking into consideration previous meaning schemes and examining the assumptions on which they are based (Mezirow, 1991). In this way, it is possible to create new meaning from prior knowledge by using newly accepted ideas that were previously inconceivable. Transformational learning takes place when previous truths are changed through the process of critical reflection into new meaning perspectives (Mezirow, 1991).

Ecological theory holds that individuals are affected by the myriad of relationships which surround people throughout their lifetime (Bronfenbrenner, 1979). Based on this theory, by examining the relationships that surround the family, from the perspective of the parents, weaknesses and exceptions may be identified and remediated. Individuals with Level 1 ASD are not obtaining and keeping livable wage employment after leaving high school or post-secondary education at a rate comparable to their non-disabled peers (U.S. Department of Labor Statistics, 2016). Some reasons for this phenomenon may be that students are unprepared, lack skills, and cannot navigate the systems. Discrimination and lack of proper transition planning are other possible explanations.

Both Mezirow's and Freire's theories apply to the parents of individuals with ASD. The parents, along with their children can be seen as being on the outside of the typical experience of life after school. The presence of ASD creates a different learning curve than that of other young people (Anderson, Liang, & Lord, 2014; Shogren & Plotner, 2012; Test, Fowler et al., 2009;

Wehman et al., 2012; Wehman et al., 2014). In turn, the experience of the parents may also be different. Freire's theory empowers individuals through knowledge (Horton & Freire, 1990) which is created through the mutual dialogue between the learner (or parent) and the teacher (or resources for information such as governmental agencies or teachers). Transformational Theory relates to adults in that they change and grow through critical reflection (Mezirow, 1991). In the case of parents, the gathering of information and sharing it is a process of transformation and reflection (Mezirow, 1991). This reflection can be accomplished not only through the individuals but also through the other people connected through Bronfenbrenner's (1979) Ecological Theory. Freire's (1970) Critical Education Theory then allows these individuals to take control of the phenomenon through their increased knowledge obtained by education. Within the current proposal I provide information about this important relationship in the process: that of the parents or guardians of the individuals with ASD.

Review of Literature

Autism Spectrum Disorder is a developmental disability that affects an estimated 1 in 68 individuals born each year (CDC, 2016). The Individuals with Disabilities Education Improvement Act (2004) mandated that school programs for all individuals with disabilities are required to have a transition plan that explains how the school and other resources will prepare individuals for life beyond high school (34 C.F.R. §300.348). After a brief discussion of the history of special education and transition, I continue the literature review with some background information and a review of refereed literature pertaining to transition programs and outcomes for individuals with ASD.

History of Special Education and Transition Programs

Kanner (1943) used the term autism to describe a phenomenon of withdrawal that he saw in several of his patients. The 11 patients, all under 10 years of age when seen by Kanner, were described by their parents as unable to relate to others in a typical way. They were most comfortable when left alone to play, had excellent rote memory, and displayed some stereotypical movements (Kanner). At approximately the same time, Hans Asperger identified a similar phenomenon with his patients in Germany; however, Asperger's paper was not well known until it was translated by Uta Frith in 1991. The two similar conditions remained separate until the publication of the Diagnostic and Statistical Manual 5th Edition (American Psychiatric Association, 2013) when a variety of disorders including Autism, Pervasive Developmental Disorder – Not Otherwise Specified (PDD NOS), and Asperger's Syndrome (AS) were combined under the heading Autism Spectrum Disorder (ASD).

School programs have developed for individuals with ASD and others with disabilities over the past 100 years. Although all states had compulsory education laws by 1918, many individuals with disabilities were excluded (Yell, Rogers, & Rogers, 1998). Case law in the United States showed instances where individuals were expelled or denied access to public education due to weaknesses of the mind, inability to properly care for personal hygiene, or unfitness as determined by school officials and based on perceived ability or unruliness (Walker v. City of Cambridge, 1893; Yell et al., 1998). The case law ruling in *Brown v. Board of Education* (1954) established that segregation of students based on race was unconstitutional. Based on this case law, advocacy groups asserted all students, even those with a disability, had the same rights to education thus applying the Fourteenth Amendment equal protection guarantee to individuals with disabilities (U.S. Const. Amend. XIV, §1).

Following the ruling in *Brown v. Board of Education*, the federal government began to create legislation which provided education for students with disabilities through the passage of a number of laws which included funding (Yell, et al., 1998). Key among the laws was the Education of Mentally Retarded Children Act of 1958 that pushed for specific teacher training to prepare them to instruct individuals with mental retardation by creating grants for post-secondary institutions. A second key piece of legislation which applied to transition was Section 504 of the Rehabilitation Act of 1973 which provided that (Section 504, 29 U.S.C. §794(a)):

> No otherwise qualified individual with a disability in the United States… shall, solely
>
> by reason of his or her disability, be excluded from the participation in, be denied the
>
> benefits of, or be subjected to discrimination under any program or activity receiving
>
> Federal financial assistance or under any program or activity conducted by any
>
> Executive agency or by the United States Postal Service. (p. 141)

Another piece of significant legislation supporting individuals with disabilities in education was the Education for All Handicapped Children Act of 1975 (EAHCA) also known as P.L. 94-142. The purpose of EAHCA was to secure the right to a free and appropriate public education (FAPE) for all children with disabilities. The law also provided funds to assist States and local education agencies (LEAs) in providing this education.

The current idea of transition began from a series of programs over a 30-year period (Halpern, 1991). In the 1960s, the approach to preparing individuals for life beyond school took the form of work study (Halpern, 1991). The focus of work study, according to Halpern, was a balance of academics, socialization, and vocational skills along with work experience to lead to positive post-school outcomes through interagency agreements. Following work study was the career education movement which initially focused on individuals without disabilities. No

concrete definition for career education was ever created (Halpern, 1991). The endorsement of the program by the Council for Exceptional Children in 1978 ensured the preservation of the career education movement for individuals with disabilities even after the repeal of the law (Halpern, 1991). A final precursor to transition as described by Halpern was a position paper from the Office of Special Education and Rehabilitation Services (OSERS) which described a transition model to facilitate movement from school to work. This program became known as the Bridges Program because the services spanned the gap between school and work. Three types of services were offered: transition without special services which used community services; transition within a time-limit where the presence of a disability qualified individuals for the service; and transition with ongoing services which lead to supported employment with job coaches (Halpern, 1991). All of these programs focused on the goal of employment; then, with the passage of Individuals with Disabilities Education Act (IDEA, 1990), transition became a program to provide academic, social, and other supports necessary to assist individuals with disabilities in life skills, social interactions, and housing as well as employment.

The new law included provisions that changed terminology, added autism as a specific eligible category of disability, and required a plan for transition by age 16 in all Individualized Education Plans (IEPs). After being reauthorized in 1997, the act was renamed in 2004 as the Individuals with Disabilities Improvement Act (IDEIA) and required that the transition plan be designed as a results oriented process leading to post-secondary education, vocational education, supported employment, adult services, independent living, or community participation. IDEIA (2004) also provided that the transition program had to be individualized based upon the needs and interests of the child. The plan, according to IDEIA (2004), must include a summary of all the specific aspects of the program and involve the student and parent in the creation of the transition

plan. IDEIA (2004) also requires that measurable transition goals assist individuals in achieving post-school plans. With the addition of measureable goals, research led to the identification of a number of best practices determined through literature review to be evidence-based, or recognized as effective through valid research methods (Test, 2012).

Background of Autism Spectrum Disorder

ASD is a developmental disability that manifests in deficits in communication, socialization, and inflexibility of behaviors (American Psychological Association, 2013). The Centers for Disease Control estimates the prevalence of ASD at 1 in 68 people (2016). The employment rate for individuals with ASD is approximately 20% (U.S. Department of Labor Statistics, 2016). ASD is difficult to remediate because of the nature of the disability; the symptoms of autism spectrum disorders, according to Seltzer et al., change in both severity and prevalence over the course of individuals' lifetimes (Sousa, 2007). The symptoms of ASD, according to Sousa, manifest differently among individuals and span a spectrum from mild to severe. The severity of ASD is labeled by the Diagnostic and Statistical Manual 5 (American Psychiatric Association, 2013) according to three levels. Level 3 is characterized as requiring very substantial support due to severe deficits in verbal and nonverbal behavior as well as strict adherence to routines or rituals which interfere with functioning (American Psychiatric Association, 2013). Individuals at this level may not communicate at all using words and may use sounds or request refusal in order to express their wishes. Level 2 requires substantial support to mediate deficits in social interactions and verbal and nonverbal communication along with inflexibility of behaviors and resistance to change (American Psychiatric Association, 2013). Individuals with Level 2 ASD may be able to speak yet not use reciprocal speech.

Individuals with Level 1 ASD may require support, including direct instruction or counseling, in order to interact with others and to organize as well as plan for daily living (American Psychiatric Association, 2013). Many individuals at Level 1 have average to above average intelligence and a wide range of strengths yet anxiety and difficulty adjusting to change affect interactions with others (American Psychiatric Association, 2013). No one transitional intervention is used for the entire population of individuals with ASD, but rather a continuum of alternatives is available (Test, Fowler et al., 2009). My focus was on Level 1 individuals who have average or near average intelligence, communication skills, and various strengths yet do not have competitive employment.

Evidence-based Practices

Several authors had identified evidence-based practices in secondary transition which may lead to better post-school outcomes for individuals with ASD (Hendricks & Wehman, 2009; Holwerda, van der Klink, Goothoff, & Brouwer, 2012; Lee & Carter, 2012; Nasamran, Witmer, & Los, 2017; Rusch, Hughes, Agran, Marin, & Johnson, 2009; Test, Fowler et al., 2009; Test, Mazzotti et al., 2009). Through the use of the National Secondary Transition Technical Assistance Center's (NSTTAC) Rules Test, Mazzotti et al. (2009) were able to classify levels of evidence associated with a list of practices as strong, moderate, or potential based on the types of experimental designs of the studies which had been conducted. Strong levels of evidence of causal inference for a practice were backed by high quality studies where all quality indicators (QIs) had been met by at least three different research teams (Test et al., 2009). Using the NLTS2 data, Nasamran, Witmer, and Los (2017) examined the extent to which high school academic achievement, as well as social skills mastery, are predictors of postsecondary success. In their literature review of transition from school to adulthood for individuals with ASD, Hendricks and

Wehman (2009) selected only those studies which showed a functional relationship between the independent and dependent variables. Holwerda et al. (2012) used literature on predictive factors and work as well as social outcomes in order to rate studies and identify forecasters of work participation.

An examination of specialized programs and the work of other researchers supported the identification and application of best practices (Rusch, Hughes, Agran, Marin, & Johnson; 2009; Lee & Carter, 2012; Rowe et al., 2015). Building on the work of Test, Fowler et al. (2009), Rowe et al. (2015) sought to operationally define the indicators already identified in order to present educators with standards through which they could create evidence-based transition programs. These authors formed a team of experts which included authors/researchers of topical, scholarly, peer reviewed work and practitioners in the areas of education and service provision, who used a Delphi procedure to gain consensus on the definitions and characteristics of programs (Rowe et al., 2015). Through surveys of a panel of experts Roux et al. (2015) took a step toward codifying practices in school transitions without detracting from the categories that Test et al. (2009) had created. Test, Fowler et al. (2009) identified 32 secondary transition evidence-based practices in transition which were confirmed and used by several other researchers (Carter, Austin, & Trainor, 2012; Mazzotti & Plotner, 2016; Roux et al., 2013; Rowe et al., 2015; Shogren & Plotner, 2012; Test, Mazzotti et al., 2009); these authors identified many broad practices which fell into four categories: student focused planning, student development, family involvement, and program structures. These categories will be explained as they are presented below.

Student Focused Planning

According to Test, Fowler et al. (2009), an effective transition practice which leads to successful outcomes was student focused planning which takes a look at the goals and interests of

the individual student. Both the Individualized Education Program and the transition program are then created around the specialized interests of individuals (Test, Fowler et al., 2009). These findings were supported by the work of Rusch et al. (2009) who found that self-directed learning and setting student centered goals were important for transition. Self-determination, self-efficacy, and self-advocacy were also found to be important predictors of positive post-secondary transition (Lee & Carter, 2012; Rowe et al., 2015).

One area where student focused planning was encouraged is in vocational rehabilitation programs which are accessed after a student leaves school; yet Burgess and Cimera (2010) and Chen, Sung, and Pi (2015) found poor outcomes, underemployment, and underutilization of vocational rehabilitation services by the ASD population. In addition, in their study of a 10-year period, Burgess and Cimera (2010) discovered that the costs were higher for ASD individuals than for other rehabilitation groups and only a mean total of 36% of individuals with ASD were successfully employed. Chen, Sung, and Pi (2015) determined that training in the use of vocational rehabilitation services might increase their use among individuals with ASD. In a later report, Test, Fowler, and Kohler (2013) suggested that further research needed to be conducted in order to build on the levels of evidence which they established.

Student Development

A second area of evidence-based practices identified by Test, Fowler et al. (2009) was student development. In this category, 25 practices were found to be documented by the evidence including: teaching life skills (i.e. purchasing, banking, job applications, cooking, grocery shopping, and home maintenance), teaching employment and life skills in the community, accessing a variety of mediums to teach employment skills (i.e. computers, coworkers), and teaching job related social and communication skills. Direct skill instruction based on needs and

continuous training were also recognized as important instructional goals by other researchers (Lee & Carter, 2012; Lindstrom, Doren, & Miesch, 2011; Test, Smith, & Carter, 2014).

Several programs were found through my literature research that focused on student development. Project SEARCH™ is a workplace based, 1-year program which combines instruction, career exploration, and hands on training (Wehman et al., 2012). Asperger Inclusion Program (AsIP) helps to transform students' self-perception through reflection and uses connectedness to foster relationships that increase independence, social integration, and employment (Moore Gumora, 2014; Odom Duda, Kucharczyk, Cox, & Stabel, 2014). Further support for developing relevant skills that enhance relationships was found by Test, Smith, and Carter (2014) when they identified factors which should be built into the scaffold of the transition program. A third program was community-based, in which coworkers with professional supports trained individuals with ASD for jobs (Cimera, 2010). This method was both successful and cost effective (Cimera, 2010). Student development and access to the community were found to be effective in all three of these community-based programs. Individuals with Level 1 ASD appear to have special challenges when they transition to work or post-secondary education; yet development of social interactions, executive functioning (problem solving), decision making, organization and identification of strengths and weaknesses were found to help produce favorable outcomes (Dipeolu, Storlie, & Johnson, 2012; Nasamran, Witmer, & Los, 2017; Test, Smith, & Carter, 2014).

Family Involvement

Bronfenbrenner (1979) found that an infant is engaged in a wide range of relationships throughout development. ASD is not usually diagnosed before 12 months of age but can be determined in many cases before 24 months. Families are then eligible for Early Intervention

Services such as speech and language therapies, occupational therapy, and physical therapy. The children still spend most of the time in the home. As children on the autism spectrum age, they can transition to preschool services at age three and elementary school at age five; while still dependent upon the family for the majority of supports (IDEA, 2004). Through the lifespan of individuals, the family provides the core support system even as they transition from secondary school to post-secondary life and beyond; therefore, a look at family supports was warranted.

Family involvement had one evidence-based practice with a moderate level of substantiation – family training on transition issues (Test, Fowler et al., 2009). Many authors identified family involvement, supports, and emotional supports as necessary for positive outcomes (Lee & Carter, 2012; Lindstrom, Doren, & Miesch, 2011; Rowe et al., 2015). DeLeo (2017) studied parental and staff perceptions of the transition process to identify areas for professional and parental development. Higher expectations by family members were also found to contribute to success (Lindstrom, Doren, & Miesch, 2011). Access to programs, including vocational programs can be hampered by limited family involvement. In a study of the effects of a family centered transition process on post-school outcomes, Hagner et al. (2012) reported an increase in expectations, self-determination, and vocational decision making through a process which included family training, individualized planning, and follow up support. Although grouped under the umbrella of secondary transition, practices aimed at transition to post-secondary education rather than employment were found to be slightly different. Professional assistance as well as family and emotional support were considered to be important for education bound individuals (Mitchell & Beresford, 2014). Nasamran, Witmer, and Los (2017) found social skills to be a predictor of success in postsecondary education, employment, and independent living.

Fish (2006) conducted a case study to determine the perceptions of parents with regard to their children's IEPs. The parents felt that they needed to persist and become knowledgeable in the area of special education in order to advocate for and achieve appropriate services for their children (Fish, 2006). They also identified a sense of negative experiences at meetings, inferior quality of services, as well as a lack of transition services that included community experiences (Fish, 2006). The themes of teacher knowledge of ASD and effective communication and collaborations between home and school have been identified as especially important by parents (Fish; Starr & Foy, 2012). Valuable information was available from parents and teachers of individuals with ASD. Parents are an integral part of ASD individuals' development from birth through adulthood, including transition from secondary school to post-secondary life. They can play a major role in the development of self-determination skills which can assist individuals with ASD in achieving successful outcomes (Carter et al., 2013; Wehmeyer, 2014).

Participation in community and social experiences is facilitated by close family and friends (Anderson, Liang, & Lord, 2014; Kirby, 2016). Both community and social participation was found by Myers, Davis, Stobbe, and Bjornson (2015) to decline from adolescence to adulthood for individuals with ASD. Using NLTS2 (National Longitudinal Transition Study 2, 2000 - 2008) data, they found that although community participation decreased from 63% to 46%, social participation remained the same. NLTS2 data did not include social media as a measure of social engagement. Family supports are required when individuals are beyond the scope of school based services. One important limitation of Myers, Davis, Stobbe, and Bjornson's (2015) study was defined as bias: both recall and information. The authors also felt that there could have been some misunderstanding of the questions by participants since the questions were administered through a survey without direct contact.

Several studies used parents as a source of information regarding their children with ASD (DeLeo, 2017; Spann, Kohler, & Soenksen, 2003; Starr, Foy, Cramer, & Singh, 2006; Fish, 2006). Professional as well as parent perceptions were compared and used to develop a training program for a rural school district (DeLeo, 2017). Parent involvement and perceptions of special education services were studied by Spann et al. (2006) who found different levels of satisfaction at various levels of education. The older the students became, the lower the satisfaction (Spann et al., 2003). This study did not include school personnel perceptions. According to the authors, some limitations of the study were the reliance on parent report of the diagnoses and inability to determine preconceptions of the volunteer subjects (Spann et al., 2003). Parent satisfaction with a wide range of educational practices in Canada was investigated by Starr et al. (2006). Approximately 50% of parents of children with ASD were satisfied with their child's educational experiences. Many also felt supports were provided less than they were needed (Starr et al., 2006).

Program Structures

A final category of evidence-based practices identified by Test, Fowler et al. (2009) was program structures, which included a variety of instruction and training options. When programs included community-based instruction and extension past secondary school, they showed a moderate level of evidence for success (Test, Fowler et al., 2009). Community-based instruction was found to be an effective practice by several researchers including Wehman et al. (2012), Cimera (2010), Moore-Gumora (2014), and Odom Duda et al. (2014). Extension of training and education after high school was also proposed by Lindstrom, Doren, and Miesch (2011).

Closely associated with community and post-secondary programming, Shmulsky, Gobbo, and Donahue (2013) examined a transition program implemented at a liberal arts college. The program was structured to connect with individuals with ASD early – before the end of their senior

year of high school. Another focus of the program was to assist individuals in acclimating to the school campus by making careful housing placements and providing specialized counseling during the first year of college. An important aspect of the program was the involvement of the parents. Mitchell and Beresford (2014) found better results were achieved by individuals who had a coordinator of transition and who made several on site visits to the institution of higher learning in order to better acclimate to the new environment Although the results of this study were difficult to generalize due to a wide range of perceptions and experiences, similar results were found by many other researchers with regard to program structures (Cimera, 2010; Moore-Gumora, 2014, Odom Duda et al., 2014; Wehman et al., 2012).

Fox (2011) used a variety of frameworks: family systems theory, ecological systems theory, and conscious competence theory combined with self-efficacy and self-determination concepts to conclude that services to individuals with ASD could be changed to include transition which extends to post-secondary education. This idea seemed to be corroborated by Myers, Davis, Stobbe, and Bjornso (2015) when they suggested that having a case manager in adulthood similar to that provided through an Individualized Education Plan (IEP) during school years may be a critical factor in obtaining favorable outcomes post school.

While evidence-based practices have been identified and codified by Test, Fowler et al. (2009), the application of those practices in actual school transition programs may be lagging. Recent work by Mazzotti and Plotner (2016); Plotner, Mazzotti, Rose, and Carlson Britting (2016); and Test, Bartholomew, and Bethune (2015) indicated that some training should be conducted with service providers to improve outcomes. Mazzotti and Plotner (2016) sought to determine service providers' knowledge and use of evidence-based practices. The authors used a snowball sampling procedure to distribute an online survey to transition providers across five states. The authors

found that implementation of the evidence-based practices was limited by provider lack of training, access, and preparation (Mazzotti & Plotner, 2016). They further found that educators and direct service transition providers reported gaining information about evidence-based practices (EBPs) from journals rather than training or education; therefore, IEP evidence-based practices were not used as often as expected (Plotner, Mazzotti, Rose, & Carlson Britting, 2016). The authors cited the use of the snowball effect as a barrier to determination of the rate of response and the extent to which the sample mirrored the population as a whole (Mazzotti & Plotner, 2016). Test, Bartholomew, and Bethune (2015) had made presentations to school administrators to suggest ways to use evidence-based practices and predictors to guide staff development and school policy.

National Autistic Society Prospects (NASProspects), a specialized supported employment program to aid individuals with Asperger's Syndrome (now Level 1 ASD) in preparing for and attaining work, was examined to evaluate the changes in numbers and types of jobs; comparing clients, economic costs and benefits; and assessing satisfaction for the program (Howlin, Alcock, & Burkin, 2005). Over an 8-year period, 70% of the 194 jobs found were for 16 plus hours per week and were sustained over 13 weeks (Howlin, Alcock, & Burkin, 2005). Many of the jobs fell into the categories of administrative, professional, or technological (Howlin, Alcock, & Burkin, 2005) which is superior to most entry level and low-level jobs reported by many individuals with ASD (Hurlbutt & Chalmers, 2004; Wehman et al., 2013).

Post-school Outcomes

School transition programs have had a myriad of outcomes. Individuals with ASD may transition to day programs, supported employment, employment with a job coach, competitive employment, or post-secondary education depending on the level of ability (Roux, Shattuck, Rast,

Rava, & Anderson, 2015). One consistent measure of outcomes, especially for individuals with

Level 1 ASD, had been employment including types of jobs, length of employment, number of

hours per week, and benefits (Roux et al., 2015). Relationship building which is taught during

transition can lead to a better social life after graduation (Gerhardt & Lainer, 2011). Included

under the heading of relationships were community connections and social connectedness (Roux et

al., 2015). Leisure activities and living arrangements were also considered aspects of outcomes

(Roux et al., 2015). The importance of activities for adults with ASD was emphasized by the large

group of people aging out of public education (Gerhardt & Lainer, 2011).

Hurlbutt and Chalmers (2004) interviewed individuals with ASD to define concerns about

employment. The authors uncovered themes of importance to the ASD individuals including: high

unemployment and underemployment as well as social skills, communication, and sensory issues.

Underemployment was described as employment which fell below the level of education or

abilities of individuals (Hurlbutt & Chalmers, 2004). The individuals with ASD recommended job

coaches, low pressure jobs, mentoring, and a job agency to match meaningful jobs with

appropriate individuals (Hurlbutt & Chalmers, 2004).

Employment and day activities have been related to behavioral functioning (Taylor &

Seltzer, 2010). The authors identified a gap in college placement for ASD individuals who had

intellectual disability (ID) as compared with those without ID (Taylor & Seltzer, 2010). In the

examination of outcomes of 66 young adults with ASD, 47% of those without ID transitioned to

college while only 2% with ID made the same transition. Another discovery was that 23% of

individuals without ID had no regular daily activities compared to 8% of those with ID. These

results could be an indication of fewer activity choices for those individuals who had a higher

functioning level. Some limitations of this study were identified by the authors including: small sample size (66), a volunteer sample, and limited ethnicity.

High unemployment and difficulty in maintaining employment were found in a sample of 73 individuals (Taylor, Henninger, & Mailick, 2015). It should be noted that racial/ethnical diversity was limited in this study and the recession of 2008, the time in which this study was conducted, may have had an effect on employment (Taylor Henninger, & Mailick, 2015). Dipeola, Storlie, and Johnson (2012) found that a process of matching careers with strengths would achieve the best outcomes, yet many jobs for individuals with ASD have been entry level, unskilled jobs often unrelated to the degrees or training of the person (Taylor, Henninger, & Mailick, 2015). Nasamran, Witmer, and Los (2017) found a link between better social skills and employment. Self-knowledge and self-advocacy assist individuals with making appropriate accommodations on their own.

The Interagency Autism Coordinating Committee's Strategic Plan for Autism Spectrum Disorder Research - 2013 Update called for longitudinal studies of how ASD manifests across the lifetime. Youth with ASD have been at a higher risk of not being involved in education or other activities in the first two years post high school (Shattuck et al., 2012). Using the National Longitudinal Transition Study – 2 (NLTS2) data, Roux et al. (2013) found that the young adults in the highest income bracket with the highest functional skills had better outcomes. In the study, one-third of the individuals with ASD were employed but had the lowest rate of full time employment of any of the disability groups examined, which included mentally retarded, emotionally disturbed, and learning disabled groups; limitations had been evident from the use of NLTS2 data which did not account for IQ or comorbidity of psychiatric diagnoses. Nasamran, Witmer, and Los (2017) suggested that there is a potential need to examine individuals who are

higher functioning because the NLTS2 data shows a lack of structured postsecondary activities for those with ASD and no ID.

The Economics of Transition Programming

The costs across a lifetime can run up to $2,000,000 for individuals with ASD (Roux et al., 2015). Included in this projection were costs of school and transition services, medical care, housing, and lost earnings of the parents as well as the individuals with ASD (Buescher, Cidav, Knapp, & Mandell, 2014). The Interagency Autism Coordinating Committee (IACC) called for research to analyze the needs of individuals who use the social services system. They also were working to create a way to analyze return on investment to develop more cost-effective programs of transition (IACC, Strategic Plan, 2013). Several researchers have examined the economic factors related to a diagnosis of ASD and sought to mediate the effects (Buescher et al., 2014; Cimera, 2010; Roux et al., 2015). Community-based training was found to be more cost effective and successful than school based training (Cimera, 2010).

Quality of life is a difficult concept to define because all individuals have a unique nature and their perceptions and values differ (The Special Interest Research Group on Quality of Life, 2000). What is an important measure for one might be unimportant to another. Current conditions can also alter an individual's perceptions according to The Special Interest Research Group on Quality of Life. Among the domains identified as pertaining to quality of life are emotional well-being, interpersonal relations, material well being, personal development, physical well being, self-determination, social inclusion, and rights (The Special Interest Research Group on Quality of Life, 2000). Although recognizing that quality of life varies from person-to-person, Biggs and Carter (2016) used a parent proxy version of KIDSCREEN 27, a health related Quality of Life questionnaire, to rate five domains: physical well being, psychological well being, autonomy and

parent relations, peers and social support, and school environment. The authors identified

religious faith, peer relations, self-determination, and out-of-school activities as helpful to positive

post-school outcomes. Quality of life was seen by Hendricks (2010) as improved by employment

as a result of the economic advantages gained.

Summary and Conclusions

Post-school outcomes for individuals with Level 1 ASD are measured by engagement with

employment and post-secondary education. The unemployment rate for this group has hovered

around 80% for the past 20 years with little, if any, improvement (Taylor, Henninger, & Mailick,

2015; Chen, Sung, & Pi, 2015). Although evidence-based practices in secondary transition have

been identified and put into use in a variety of programs, for the most part individuals with Level 1

ASD continue to have little success in the post-school arena.

The literature concerning transition programming for individuals with disabilities, in

particular those with ASD, had focused on evidence-based practices for programs (Hendricks &

Wehman, 2009; Nasamran, Witmer, & Los, 2017; Rusch, Hughes, Agan, Marin, & Johnson, 2009;

Test, Fowler, et al., 2009). The outcomes for individuals with ASD have not improved

substantially over the past twenty years (Taylor, Henninger, & Mailick, 2015; Chen, Sung, & Pi,

2015). Traditional transition programs appeared to be less impactful on the post school outcomes

than once thought. Rather than viewing deficits in individuals with ASD, transition programs

should be based on the interests of the individuals while supporting their goals and dreams of a

better future. The perspectives of parents about the current state of ASD, transition programs, and

society in terms of Ecological Theory, Critical Theory, and Transformational Theory created a

case for a new reality in transition for individuals with ASD which lead to a new, improved

worldview. Through the study of parental transition experiences, it was possible to determine commonalities which lead to better outcomes and can be used to improve transition programming.

Primary practices supported by the research included parental support and involvement (Biggs & Carter, 2016; Carter, Austin, & Trainor, 2012; DeLeo, 2017; Dipeolu, Storlie, & Johnson, 2015; Lindstrom, Doren, & Miesch, 2011; Test, Fowler et al., 2009; Test, 2014; Wehman et al., 2014). A case study that used living wage data found a number of common themes that improved career development for individuals with disabilities (Lindstrom, Doren, & Miesch, 2011). Among the themes were strong self-esteem, self-efficacy, specific career expectations, family support and expectations, advocacy, and intentional career activities (Lindstrom, Doren, & Miesch, 2011). Work experiences and parents having high expectations of their child with disabilities were linked to the creation of better outcomes. Project SEARCH, which was created at Cincinnati Children's Hospital as an internship program for individuals with disabilities was studied and enhanced for people with ASD (Wehman et al., 2013). The project was designed as a model to connect students with disabilities and their parents with work supports (Wehman et al., 2013). The value of family supports in areas of acceptance, leadership, and advocacy were determined to be important (Test, Smith, & Carter, 2014). Since parents are an important part of the transition picture, their perspectives on the process as a whole are important (Kirby, 2016).

Chapter 3: Research Method

The purpose of this study was to describe the experience of transition from the perspective of the parents or primary caregivers of individuals with ASD. The focus of the study was parent perceptions of the transition programs. The emphasis was on the activities and supports which may have been provided by the school districts or any community or government agencies. Through personal interviews and a focus group, parents were able to delineate the needs and supports which were provided by the transition plans and explain their satisfaction or dissatisfaction with the services. Parents were also able to report the present status of their families. Although refereed research relating to best practices in transition from school to life for individuals with ASD was available, there were very few studies that discussed how the programs have led to positive outcomes as measured by successful employment, independent living, leisure activities, and social interactions after school.

The problem was that the status has not improved for adults with ASD who have completed the transition process. Through the study of parental transition experiences, it was possible to determine commonalities which can lead to better outcomes and be used to improve transition programming. My selection of a phenomenological approach was guided by Creswell (2013) to explore, in depth, the essence of the experience of transition through the eyes of the parents or primary caretakers of individuals with ASD. The findings of this study may provide insight into appropriate supports and services that produce positive outcomes.

In Chapter 3, I examine the process of phenomenology and the application to a study of parent perspectives. In addition, I describe the role of the researcher as the parent of an adult with ASD who has completed transition, college, and joined the workforce. The research questions helped guide the examination of the experience of parents in the process. I discuss the research

design and rationale, the methodology including participant selection logic, procedures for

recruitment, participation, and data collection, as well as the data analysis plan. Finally, issues of

trustworthiness are discussed, followed by a summary.

Research Questions

The research questions for this study were:

1. What are the lived experiences of parents and caregivers of individuals with ASD who

   have completed a transition program from school to post school?

2. With what aspects of school programs were parents satisfied?

3. With what aspects of school programs were parents dissatisfied?

4. What resources are needed for transition programs to be successful?

Research Design and Rationale

Within this phenomenological study, I explored the underlying construction of the lived

experience of transition from the parent and caregiver perspective. According to Creswell (2013),

phenomenology is an appropriate research design to deeply understand experiences that are not

observable. The experience of transition is a completed event which can only be encountered

through the recollections of the participants. In part, the goal of this research was to understand

the experience of the caregiver in order to have a more accurate picture of the needs of families of

individuals with ASD. I also analyzed the experiences to provide information about

commonalities which may lead to a better understanding of needs in this area (Creswell, 2013;

Merriam & Tisdell, 2016).

Phenomenology was chosen to examine the experiences of transition to determine what

happened and how it was perceived (Burke Johnson & Christensen, 2014). The use of at least

seven individuals provided a broader field of information about how the participants experienced

transition as compared with a case study which would examine one or more cases in depth while involving cross-case analysis (Burke Johnson & Christensen, 2014). Whereas a case study would look at a bounded system, for example an event that has a definite beginning and end, phenomenology referred to a broad experience that may be different for each participant.

The primary source of information for a phenomenological study, according to Merriam and Tisdell (2016), is the semi-structured interview which provides the opportunity for individuals to express their innermost feelings. Parents, who were the participants in this study, are part of the transition team as provided by federal law; therefore, their perspectives provide important information about transition services (IDEA, 2004). As young adults graduate from high school or college, they usually take the next steps toward independence by obtaining a job, living independently, and starting a family (Arnett, 2015). In the case of individuals with ASD, these milestones happened infrequently as compared with their nondisabled peers (Biggs & Carter, 2015). Many young people with ASD do not find competitive employment; some estimates make that number less than 25% as compared to 95% for the total population (U.S. Department of Labor, 2016).

Role of the Researcher

I was the only researcher in this study and, as such, I collected and analyzed all data. Initially, to identify participants, my role as the researcher was to contact both ▮▮▮▮▮▮▮ and ▮▮▮▮▮▮▮, to gain their assistance in locating potential participants. Although I had been a member of both organizations on and off for approximately 20 years, I did not have personal contact with individual members unless I attended workshops or conferences where I was one of 200 or more attendees in the room. Both organizations agreed to facilitate access to their membership in order to conduct this research.

After identification of possible participants, my role as researcher was to determine those who fit the basic criteria for inclusion in the study as determined by the demographic information collected through Qualtrics. I also conducted interviews in private at my local library using the protocol (Appendix E). The focus group took place at the local library as well and used the predetermined questions (Appendix F). My role with regard to the focus group was to encourage interaction and sharing of feelings and beliefs to uncover a clear understanding of the phenomenon (Kitzinger, 1995). Prior to the interviews and the focus group, I explained the study and answered participant questions. I also used memoing, the recording of reflective notes during the interviews, data processing, as well as transcription of each interview within 48 hours of collection as suggested by Merriam & Tisdell (2016). As a learning consultant, I have had extensive experience speaking with and interviewing the parents of individuals with disabilities although I did practice the interview protocols and questions (See Appendices E & F) prior to beginning. My role was to gather data from the survey, interviews of participants, the focus group, and observations (Creswell, 2013).

As the parent of an adult child with ASD who had already experienced this phenomenon of transition, I acknowledged that I have a perspective in this study which Merriam and Tisdell (2016) recognized as an important inclusion. My experience led me to certain conclusions about the topic. Through the process of bracketing, I was reminded to put aside these preconceptions while examining the data through the eyes of the participants only (Creswell, 2013). Bracketing was achieved through memoing and reflection throughout the process (Tufford & Newman, 2010). The purpose of the research was to inform based on the life experiences of the participants not the researcher.

Methodology

In phenomenological research, the aim is to find the commonalities of an experience (Merriam & Tisdell, 2016). Initial contacts with the participants were through ███████ and ███████. A letter explaining the study (Appendix C) was distributed by both organizations to appropriate prospects. I identified participants as they contacted me and assigned participants to interviews or the focus group. I then gathered information through a Qualtrics survey, semi-structured interviews, and a focus group. The interviews and focus group were recorded and prior to transcription, I listened to the recordings to become familiar with the material. Through a comparison of the recordings and notes taken at the time of the interviews and focus groups, the transcriptions were proofread.

After gathering the data, I organized it by identifying common themes to tell the details of the experiences of the participants (Creswell, 2013). The process of coding began with a review of the transcripts of the interviews and focus group to identify essential terms within the data (Burke Johnson & Christensen, 2014). The words of the participants were used to create the categories. Within the methodology section I explain the coding process that was used.

Participant Selection Logic and Procedures for Recruitment, Participation, and Data Collection

Consideration was given to the population and phenomena which were appropriate to the focus of this research study (Burke Johnson & Christensen, 2014). Since I wanted to discover the parents' perspectives of the transition programs, I first identified organizations associated with ASD and then approached them to obtain permission to access their membership. Purposeful sampling was conducted to gather as much data as possible (Merriam & Tisdell, 2016). In this method, participants were selected in a way as to provide as much information as possible without

sampling an exhaustive group (Merriam & Tisdell, 2016). I recruited 13 participants; seven were

interviewed, five were in the focus group, and one was an alternate in case anyone voluntarily

dropped out of the study. One person did drop out of the focus group and the alternate

participated.

The aim was to discover the deep-rooted feelings of the participants, as well as

presuppositions, and views on the topic of transition (Merriam & Tisdell, 2016). According to

Merriam and Tisdell, the interview is appropriate when the topic is past events which cannot be

observed. In addition, the interview drew out the deep feelings, beliefs, and perceptions of the

participants which also could not be observed (Burke Johnson & Christensen, 2014). Participants

were eligible for inclusion in the study if they were the parent or primary caregiver of an individual

with high functioning autism, PDD NOS, Asperger Syndrome, or Level 1 ASD as described by the

Diagnostic and Statistical Manual 5, who had also completed a high school transition program and

was between the ages of 18 and 30. Through the use of these criteria, it was possible to collect

specific data which would provide a plethora of information about the experience of parents and

caregivers (Merriam & Tisdell, 2016). Through the study of parental transition experiences, it was

possible to determine commonalities which lead to better outcomes and improve transition

programming.

First, a letter describing the study and methods of gathering information (survey, interview,

focus group, audio and video recording) was distributed by ███████ and ███████ to

potential participants to gather a minimum of 12 individuals for the phenomenological study. This

number was chosen based upon Creswell's (1998) suggestion that phenomenological research

should use between five and 25 participants. I planned to conduct interviews with seven

participants and hold one focus group with five participants. In addition, I had one participant in

case someone left the phenomenological study. Purposively chosen participants were given 10 days to confirm their agreement to take part in the study.

The size of the sample for inclusion in the study was 12 parents (Creswell, 1998; Morse, 1994). Initial contact was made by the potential participant to indicate to me their interest. Next, I met individually with the volunteers for 15 minutes to review the consent form and answer any other questions. At this time, if the participant was in agreement, the initial one hour interview was scheduled.

Data collection was accomplished through a Qualtrics survey (Appendix G), personal interviews (Appendix E), and a focus group (Appendix F). Creswell's (2013) suggestions for data collection from interviews were followed. First, open-ended questions were developed for the interviews and the focus group. Next, the interviewees and focus group participants were selected based upon their ability to meet the criteria of having experience with the phenomenon (Creswell, 2013). Participants completed an online survey through Qualtrics which provided demographic information. The interviews were recorded so that verbatim transcription was possible. The interviews were used to expose participants' deep perceptions and attitudes.

The focus group was audio recorded as well as videotaped to ensure that ideas and quotes were attributed to the correct informants (Creswell, 2013; Merriam & Tisdell, 2016). The purpose of the focus group was to identify common trends among the participants. The group discussion assisted participants in producing ideas and exploring the concept of transition programs.

Instrumentation

Part of the study used demographic information such as age, size of family, level of education, which was collected through a Qualtrics survey (Appendix G). Other data was collected through semi-structured interviews using a tool that was researcher-created (Appendix E)

and allowed flexibility in questioning and answering (Merriam & Tisdell, 2016). A focus group was also conducted using researcher-created questions (Appendix F) to elicit more information in a limited timeframe. As the purpose of the study was to find out how the parents of individuals with ASD perceived the experience of their child's transition and adaptation to the world beyond school, it was important to allow broad answers to questions (Burke Johnson & Christensen, 2014). The purpose of the focus group was to collect impressions of the services provided by transition programs and a collaborative insight into the lived experiences (Burke Johnson & Christensen, 2014).

The questions for both the interviews and focus group (Appendix E or G) were self-designed by me based on the suggestions of Janesick (2016) and the goal of the phenomenological study to discover the unique experiences of parents and caregivers of individuals with ASD after completing transition from school to post school (Janesick, 2016). I based my self-designed survey questions on the ideas of Bronfenbrenner (1979), Freire (2000), and Mezirow (1991). Janesick suggested five to seven open-ended questions that uncover the big picture based on the research question with follow up and comparison questions. I also queried for examples and to clarify answers (Janesick, 2016).

Data Analysis Plan

Constant analysis while collecting data enabled a more controlled study while avoiding a buildup of data and backlog of processing; therefore, data analysis began with the initiation of the interviews and focus group (Merriam & Tisdell, 2016). As each interview was conducted, I audio recorded the session using an IC digital voice recorder, and had on hand a Sony audio recorder and extra batteries. I created field notes and recorded observations within 24 hours of

completion of the interview (Creswell, 2013; Merriam & Tisdell, 2016). The focus group was audio as well as video recorded to assist in the transcription process (Creswell, 2013).

Following the suggestions of Creswell (2013) and Moustakas (1994),

1. I transcribed verbatim all personal interviews and the focus group in my private, home office. The individual reports of the interviews were reviewed through member checking to assure that the essence of the unique experiences were recorded correctly.

2. I coordinated the information with the observations made at the time of the interviews and focus group. The process of memoing, a reflection by the researcher on the information collected, was used to maintain an understanding of what was shared and reduce the possibility of bias (Groenewald, 2004).

3. The next step was the initial coding where I identified important statements of the interviewees in a process that Moustakas and Creswell call horizontalization.

4. As the purpose of the research was to identify the unique experiences of individuals, the data was compared. Through a process of reduction and elimination, the repetitions were removed and the essential parts were clustered and divided into themes called meaning units (Moustakas, 1994; Creswell, 2013).

5. The next step, which Moustakas calls textual description, was a detailed description of what happened incorporating the words of the participants.

6. Subsequently, a description of how the phenomenon was experienced, or what Moustakas (1994) refers to as structural description, was written including the where and when of the experience.

7. The final step in the process was a description incorporating both the textual and structural descriptions of the phenomenon from each participant to illustrate the essence of the experience (Moustakas, 1994; Creswell, 2013).

Trustworthiness: Internal and External Validity

Burke Johnson and Christensen (2014) explained that validity refers to the accuracy of the interpretations made from the data. Merriam and Tisdell (2016) referred to credibility rather than internal validity. They discussed credibility as believability or matching with reality (Merriam & Tisdell, 2016). To determine credibility, the researcher can use a variety of methods. Triangulation of data can be achieved through enough sources as to provide a wide view of the topic. In this case, I used a Qualtrics survey of the 12 participants, seven personal interviews, and five individuals in a focus group to complete triangulation. Member checks where participants review the findings and provide feedback were also used alleviate misinterpretation of the data (Merriam & Tisdell, 2016). The practice of reflection also allowed me to rule out biases in reporting (Merriam & Tisdell, 2016).

Merriam and Tisdell (2016) suggested that external validity or generalization of the findings of a qualitative research study is not provided by the researcher, but rather the reader. My role as the researcher was to provide sufficient description to allow the reader to determine the similarity of the situations and therefore, transferability of the results (Merriam & Tisdell, 2016). Another way to ensure external validity is through accessing a diverse sample in order to provide a broad description of the phenomenon (Burke Johnson & Christensen, 2014).

Dependability

Since the results of this phenomenological study will paint a picture of the experiences of the specific participants at a particular, past time, it would be difficult to conduct the research

again with a different group and get the same results. According to Shenton (2010) dependability can be addressed by providing a detailed description of the process used to conduct the research to enable another researcher to repeat the process with a different sample group. The detailed description also allows the researcher to show that proper research practices have been followed (Shenton, 2010). To accomplish this, I provided a thorough description of the research design and the process of implementation along with the previously mentioned detailed description of data gathering and reflection (Merriam & Tisdell, 2016).

Confirmability

In qualitative research, confirmability is reliant on the ability of the researcher to demonstrate the absence of error and bias in reporting the results (Shenton, 2010). The researcher can achieve this through the creation of an audit trail wherein I described the process of data collection through journal and memoing (Burke Johnson & Christensen, 2014). This created a running record of my ideas about the data as they arise. I kept a journal, memoed, and conducted member checks to ensure that the essence of the participants' experiences was the focus of the results.

Ethical Procedures

To meet the qualifications of ethical research, informed consent was obtained (Creswell, 2013). The volunteer participants were informed that they were participating in a research study. The purpose of the research study was explained along with the procedures. Participants knew any risks or benefits of the research. The participants understood that their participation was voluntary and that they could withdraw without penalty at any time. Confidentiality was ensured by assigning each participant an alphanumeric symbol which identified the participant by letter and date of the interview only: such as A 3.8.2017 (Merriam & Tisdell, 2016). A pseudonym was also

assigned to each participant. Another important consideration was to protect the participants from any harm (Ritchie & Lewis, 2003). Conducting the interviews in private as well as assigning a code to each participant kept the responses confidential.

Summary

Chapter 3 explained the research design, rationale, and methodology of this phenomenological study. When a person is diagnosed with ASD there are many individuals who are affected. Throughout the lifetime of the person, their parent or primary caregiver has unique experiences including the transition of their child from school programs to post-school life. The review of current, refereed literature identified numerous best practices in transition programming; however very little described the perspectives of parents or primary caregivers. In addition, although projected outcomes and data are discussed, there is limited data about personal stories relating to actual individual results.

Participants were approached through the memberships of ████████ and ████████. Only individuals who met the criteria: parent or primary caregiver of an adult with ASD between 18 and 30 years old who completed a high school transition program were included. The semi-structured interviews and focus group using researcher-created protocols were then held and the transcripts of both were documented. The data analysis plan was presented, which was conducted through a process of coding, reflection, and member checking, based on the suggestions of Creswell (2013) and Merriam and Tisdell (2016),   Issues of trustworthiness were addressed. Records of the agreements, researcher-created protocols, and other documents introduced in the chapter are included in the appendices.

Chapter 4: Data Analysis and Results

In this study I explored the experience of school transition from the perspective of parents of adults with ASD who had completed the process. Through a phenomenological study data were collected to answer the primary research question: What are the lived experiences of parents and caregivers of individuals with ASD who have completed a transition program from school to post school?   Further, I attempted to identify the aspects of the school programs with which parents were both satisfied and dissatisfied. Finally, parents were asked to identify transition practices which would lead to success.

The unique occurrence of the phenomenon of school transition was interpreted by the parent who experienced it based upon a unique world view; therefore, this phenomenological study described how the participants experienced the phenomenon of school transition (Merriam & Tisdell, 2016). As Creswell (2013) described, the ultimate goal was to provide for the reader a description that helps them to understand what the experience was like for the individuals involved in the phenomenon.

In Chapter 4, I discuss the data that were collected and the process of analysis. Finally, the results are presented with description of the patterns, associations, and themes. The conclusion of the chapter contains evidence of trustworthiness, validity, transferability, dependability, and confirmability.

Description of the Sample Demographics

Participants for the study were obtained through postings with ███████ and ██████████, organizations devoted to information dissemination, education, and support of families affected by ASD. Although membership in the organizations is not limited to New Jersey residents, the participants for my study, of necessity, all lived in New Jersey. Seven participants were needed for

the personal interviews, while five additional participants took part in the focus group. When one member assigned to the focus group had to drop out of the study, an alternate was used for the focus group. Of the 12 participants, two were male and 10 were female. A male participant took part in the focus group and one was interviewed. All participants were the parent of an adult with ASD.

Important information collected through the Qualtrics survey included information about the age, education, and work experience of the adult children of the participants which is summarized in Table 1 through Table 4 found in Appendices H through K. The age of the children (Appendix H) can shed light on the experiences of transition since IDEA was in its infancy when some of the children began transition. The parent of the 30-year-old did not remember any transition programming, just a statement that he would attend college and that was all. In contrast, the parent with the most recent graduate from high school remembered speaking with the team about her child attending college. One possible theory is the memory fades as parents become more removed from the experience.

Table 2 (Appendix I) shows the age at which the children completed school transition which can happen at any time between the ages of 18 and 21. Transition begins for individuals with IEPs at the age of 16; so, if a child leaves school at the age of 18, they have had two years of transition while if they exit school at 21, they have had five years of transition. The age of transition completion may be related to college completion as the four students who left secondary school at the age of 18 completed 4 years of college (Appendix J). Some parents indicated that they would not have let their child exit secondary education until they felt they were ready for the world. Each of these participants also related that they were highly involved in their child's education, attending all meetings from preschool until their children left secondary education.

Half of the participants' children attended college or trade school after completing

transition as seen in Table 3 (Appendix J). Although 58% of the participants' children work, the

majority of the work is only part-time. (Appendix K). The parents explained that they worked

with their children to identify possible employers and even made some work connections for them.

Only one parent stated that their child lived independently; although others stated that the living

arrangements were economically based. There was one parent who reported that her child would

always live with her. Many were concerned that their children might be victimized by others if

they were on their own.

Research Methodology

The participant sample of 12 was obtained through email blasts and advertisements on the

websites of ████████ and ████████. Prospective participants contacted me to indicate their

interest in the study. The target population was defined as parents of adult individuals with Autism

Spectrum Disorder (ASD) who had completed school transition. After I ascertained their

qualifications for the study, data collection began when each participant completed an online,

anonymous survey. The participants were randomly assigned to either the focus group or personal

interview and then assigned a pseudonym. Interview participants were assigned pseudonyms

beginning with the letters A through G based upon their order of joining the study. Participants

agreed to the assigned names. Focus group participants were randomly assigned pseudonyms; I

assigned random, alternate names to each study participant.

Personal interviews were held at mutually convenient times and each was audio recorded.

Transcriptions were provided to the participants within three days and reviewed as member

checks. There were no changes required. One focus group session was held which was video and

audio recorded. It was transcribed and member checked by two participants. Again, there were no changes required.

Data Analysis

After each recorded interview, I transcribed the data within 48 hours. The transcripts were then sent to the participant to be member checked. The focus group was audio and video recorded. The data were transcribed and sent to two participants for member checking. Coding began using the suggestions of Creswell (2013) and Moustakas (1994).   Memoing, a reflection by the researcher, was used to maintain an understanding of what was shared and to reduce the possibility of bias (Groenewald, 2004). I used a list of pre-selected codes based upon the Literature Review to begin the process. Horizontalization allowed me to identify important statements made by the participants. Data were then compared to assist in identifying the unique experiences of the individuals. Repetitions were removed and the essential parts were then clustered into themes.   A detailed description of what happened was created from the collected data incorporating the words of the participants. The structural description of how school transition was experienced followed, leading to the essence of the lived experiences of the parents.

Research Results

Beginning with a diverse understanding of transition, both the interviews and the focus group were designed to answer the primary research question: What are the lived experiences of parents of individuals with ASD who have completed a transition program from school to post school? Initial questions from both the interviews and focus group asked parents about the goals of the transition plans in their children's IEPs, as well as specific practices that were part of the program. The next group of responses centered on aspects of transition with which parents were satisfied, followed by aspects with which they were dissatisfied. Finally, responses were collected

to determine parents' suggestions for how their children's program could have been improved leading to greater success. The following represents an analysis of the data based upon the research questions.

Question 1

What are the lived experiences of parents and caregivers of individuals with ASD who have completed a transition program from school to post school?

Parents felt they did not have a true understanding of all of the aspects of school transition. Many felt their child study team members did not inform them of the definition of transition, nor did they create programs for children that would truly assist them after graduation. Parents thought that the majority of the work involved with preparing individuals with ASD for life after school fell to the families of the children, now adults. Even after applying to community and government agencies for assistance, parents were left doing the legwork and, often were denied any supports for their children. It was posited by one parent that if individuals with ASD are higher functioning, they are not provided services by schools or agencies.

Question 2

With what aspects of school programs were parents satisfied?

An important part of transition identified as positive was the inclusion of their child in the meeting process. Several even recalled that their child was a big factor in the decision- making process. Amy related that, "We left it up to R" and that any suggestions at the meetings were directed to R, her son, for a final decision. Parents felt their children gained self confidence and experience when they made decisions at this time.

Eva praised her son's school for allowing him to get and keep friends. She credited his success with the fact that he went to school with other individuals with the same diagnosis. She

believes that "athletes hang out with athletes, musicians with musicians, and individuals with ASD with those with ASD." One parent suggested that Eva's son's placement in an out of district school for children with ASD and other disabilities contributed to his success in this area.

Several parents spoke of home programs that had been provided by their school districts throughout their school experience. The home program, which can include one-to-one instruction in academics, social skills, and behavior interventions, was used in a variety of ways. In one instance it was employed to improve social skills; in another it was used to increase the individual's ability to use public transportation.

Some parents described meetings with the school district where the district personnel deferred to the parents and students about transition goals and activities. Many participants stated that they made up their own programs or that their suggestions were accepted by school personnel. Some indicated that previously adversarial relationships with the district became easier only after mediation. The participants saw this as a positive: displaying the districts' openness to various ideas and their admission that they did not know everything.

Question 3

With what aspects of school programs were parents dissatisfied?

Many parents felt that the transition goals included in their children's plan were unrealistic or nonexistent. Nine participants indicated that the whole of their children's transition plan stated they would go to college. One child's IEP stated that he would work and go to school part-time. Another student's plan indicated she would work after graduation from high school; however there was no training provided. Her parent, Rhoda, explained that her daughter went to vocational school after graduating and that they received no help from any school or government agency.

Another area of dissatisfaction was in the lack of individualization in the planning. All parents at the focus group remembered receiving what was supposed to have been an individualized guide to transition. Upon comparison, they had been given the same exact booklet. Parents felt that case managers in the schools did not spend sufficient time with the children to really get to know them. Rhoda related that at the transition meeting, the case manager "only spent one minute to ask what she liked." Rosita lamented that her son was stuck in classes that he was getting nothing out of, like Robotics, "because of the schedule." One parent was told that "special needs students don't take foreign language; they take study skills." In all these cases, parents reiterated the absence of individualized programs stating their children often received what the district had, rather than what the children needed.

Many parents mentioned social skills training or social and emotional support as important aspects of their child's program that were missing. Amy stated that most of her son's social skills were addressed in social groups outside of school. Parents felt that without their input, teachers and school staff would overlook their children's struggles. Several parents described incidences of bullying that were observed by others and still not handled appropriately by school staff. Participants felt their children are not skilled at communication and social interactions which sets them up as targets. Parents identified lack of social skills as an important factor in their success or failure as well as their happiness.

Community resources are part of the transition plan also. Parents discussed that their children were referred by their school districts to the Division of Vocational and Rehabilitation Services (DVRS). This agency provides training, supported employment services, and job coaches for individuals with any type of disability. It is their practice to become involved with students after they exit the school system. Each participant whose child tried to access supports

and services from DVRS reported a negative experience. One frustrated parent explained her child learned "what not to do."

Gianna described her transition coordinator as "nice, but not helpful." Parents complained that their case managers did not have the knowledge necessary to steer their children through transition to life beyond school. Many parents felt they, themselves, had created the transition plans for their children as well as the community connections they needed to seek employment.

Question 4

What resources are needed for transition programs to be successful?

The majority of participants in the study agreed that transition programs should be expanded to begin earlier and even extend beyond graduation from secondary school. Parents felt that since their children with ASD often take longer to learn things, preparation for life should begin earlier. Along with this idea, many thought that transition programs ended just when the hard work and support are needed. They expressed a feeling of "falling off a cliff" right after graduation because "there is nothing." Children who had been supported all their lives are sent off to find their way in the world and they are not ready to do it.

A related issue expressed by participants is that schools should prepare the children *for something*. Once children leave secondary education, Gianna felt, "the parents must find things for their child." If children are given vocational evaluation during transition, then schools can begin training them for something like a job or further education. Participants saw school as missing the point in the transition of individuals with ASD who have average to above average intelligence and many scattered skills. Students, parents felt, would do better with on the job training where they have the ability to practice the skills over an extended period of time.

Another important resource that parents suggested was to build community relationships, so students would be able to access internships or training while they are still in school. Many participants described limited community involvement in their school programs. Several participants related that their children had work experience because the parent went out and sought help from someone with whom they had connections. Others discussed their children being forced into the same work experience two years in a row because there were no other options. One child bagged groceries in a supermarket for two years. Although many participants' children had work experiences, none were offered continuation of employment after graduation.

Closely associated with community relationships is the concept of social skills training referenced by all 12 participants. Although they felt no one could be prepared for every social situation, parents thought more could have been done to develop the social skills necessary to achieve success in the world. As part of this issue, parents repeatedly mentioned "disclosure" as a deficit for their children. Disclosure relates to the choice by individuals to share with others, employers or acquaintances that they have a medical condition known as Autism Spectrum Disorder that sometimes makes ordinary daily experiences difficult. Five of the participants discussed that their children refused to disclose which sometimes lead to misunderstandings at work and often, loss of a job. Parents thought that if their children were better prepared socially, in high school, they might take the step toward disclosure which would help to provide ADA (Americans with Disabilities Act) accommodations later in life.

A final resource that parents felt districts should develop was mentors, both for the students and the parents who are trying to navigate the process. Dana wanted the district personnel to "walk side-by-side" with her and "not just push you out the door." Much of the discussion about

navigating the process revolved around needing a knowledge base or someone who has been there to assist with the transition process.

Summary of the Findings

Initial coding was focused on parent experiences of the evidence-based practices reported by Test, Mazzotti, Hendricks, & Wehman (2009) including: student focused planning, program structures, student development, post-school outcomes, family involvement, and community involvement. Many of the evidence-based practices were identified by parents as missing from their programs. Other themes became apparent as the data were compared including: likes, dislikes, social skills, anxiety, disclosure, unknown supports, and suggestions. Parents' understanding of the definition of transition was also included.

Interviews began with a discussion of the participants' understanding of the definition of school transition services compared with the definition from IDEA (2004). Individual participants described their understanding of transition in more general terms. Amy [pseudonym] said that transition in public schools includes, "meet[ing] with a teacher to go over…life skills." Gianna's definition supports this view of transition as life skills as she described supervised visits to community sites and use of public transportation. The skills focused idea of transition is in contrast to others' conception of transition as preparation for a new phase of life where supports would be few and expectations high. Transition in this interpretation includes social and communication development as well as educational preparation to be sure the individuals have an "understanding [of] the rules in each setting," as Barbara explained. Although IDEA (2004) does not require it, Frank felt that the parents should have some sort of training as well. Perhaps a good summary of the transition programs was presented by Elizabeth when she called it, "a roadmap or guideline for how the student is going to get from being a student to a stable member of society."

Although the IDEA definition of school transition describes the last few years of secondary education, most parents spoke of transition as the time after a child leaves secondary education. Many also felt like their children and the families continued to transition as they moved along life beyond school. The parents saw what the schools did in skills development, but felt that the true transition work was accomplished after their children left secondary education and were in the real world with no supports.

The participants in this study found only a few aspects of transition with which they were satisfied. They highlighted as favorable inclusion of both themselves and their children in the transition process through participation in meetings. Several parents identified access to home programs provided by their districts as very beneficial to skills development. Unfortunately, only a small percentage of families received this service. Parents of children who had been placed in out of district schools explained that their children had the opportunity to bond with others with the same disability, interests, and abilities.

Participants identified dissatisfaction quite easily. Many felt the goals of their children's transition programs were insufficient. Some discussed the absence of goals completely. Individualization within the programs was cited as a negative by parents. They referenced plans which were the same for all students with ASD as well as services which were denied to their children because they had IEPs. Another aspect of transition with which parents were dissatisfied was the limited access to social skills training which they felt was an important part of education for children with ASD. Community resources for internships, job experiences, and community-based instruction were also flagged by parents as limited. They felt that school systems should put more effort into creating partnerships with community resources. A final aspect of transition which parents discussed was the knowledge-base of the transition team members. Participants,

who were all looking for guidance, felt the professionals who were responsible for transition did not have knowledge of the process or services available to be proper facilitators.

Parents provided a number of suggestions which they believed would improve transition programming. They overwhelmingly believed transition should begin earlier. Instead of beginning transition in high school, participants strongly suggested beginning in middle school. Since individuals with ASD may take longer to learn some skills, these participants felt they should begin earlier. Associated with this, parents also thought their children, who were not going to attend college, should be prepared for a particular future endeavor, for example, woodworking or automotive.

Community partnerships were also mentioned as an area that can be enhanced. Many of the parents involved in this study created their own connections for their children. They suggested that school districts spend more resources creating these partnerships. Another area that participants felt should be developed was social skills programs. As individuals with ASD all have social skills deficits to some degree, parents thought more should be done to address this need. Parents also mentioned the need for more knowledge on the part of the professionals engaging in transition programming. They felt that short of additional training, districts should set up mentorships using parents who have already completed transition to assist those just beginning.

Validity and Transferability

If validity can be equated to believability or matching with reality, then the report of the experiences and thoughts of the participants represents a valid study (Merriam & Tisdell, 2016). Triangulation was achieved through the use of an online survey, seven interviews, and a focus group. Member checks were performed on the transcripts of the interviews and focus group and

were found to be accurate (Burke Johnson & Christensen, 2014). At appropriate times, I also reflected on the information that was being reported.

My role as the researcher has been to provide sufficient description to allow the reader to determine the similarity of the situations and therefore, transferability of the results (Merriam & Tisdell, 2016). The information provided through the interviews, focus group, and survey may be useful to others in determining the efficacy of their own transition programs. The experiences of this group of individuals will be different from the experiences of others; however, sufficient evidence was found of similar experiences among the participants to suggest that others may find similarities as well.

Dependability

According to Shenton (2010), dependability can be addressed by providing a detailed description of the process used to conduct the research to enable another researcher to repeat the process with a different sample. Chapter 4 describes the process from identification of participants, through data collection, coding, data reduction, and reporting. The survey, interview, and focus group questions are contained in Appendices E, F, and G.

Confirmability

Confirmability is reliant on the ability of the researcher to demonstrate the absence of error and bias in reporting the results (Shenton, 2010). I have documented the collection of data and member checking. I also kept track of my thoughts as I worked through the data and my analysis relied solely on the words of the participants. The codes created were taken from the words of the participants as well.

Summary

Chapter 4 began with an overall view of this phenomenological study which was designed to examine parent perspectives of the transition programs experienced by their children. The research questions were formulated to ascertain the aspects of transition with which parents were satisfied and dissatisfied. Participants were also asked to make suggestions to improve transition. The sample consisted of 13 parents of adults with ASD. This phenomenological study relied on survey, interview, and focus group data collection. The process of data analysis focused on describing the lived experiences of parents of adults with ASD who had completed school transition by identifying, through their own words, the essential experiences. Parents did not have a common definition of school transition although one is provided in IDEA (2004) and their children all experienced it.

Participants were satisfied with some aspects of transition including: district openness to parent and student suggestions, family and student involvement in meetings, home programming, and the possibility of making friends. Many of the parents were dissatisfied with the levels of individualization, social skills training, community supports, and knowledge that they cited as missing from the programs. There were many suggestions for resources that participants felt are needed for transition programs to be successful. Mentorships, community involvement, and beginning programs earlier were among the suggestions.

In Chapter 4, the process of analysis was explained and the summary of the findings was presented. In Chapter 5, I discuss the results, their relation to the literature, conclusions and recommendations.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this phenomenological study was to explore the lived experiences of parents of adults with ASD who have completed school transition programs to determine aspects of those programs with which they were satisfied or dissatisfied. Further, participants in this study were asked to suggest resources that would have improved their children's programs. The study was conducted because although there were studies identifying best practices in transition, there were few refereed research studies of the outcomes of transition practices from the perspective of the parents of individuals with ASD.

Fundamental findings of this study include: the absence of a common understanding of the term transition, both satisfaction and dissatisfaction with aspects of transition programs experienced, and participants had a number of suggestions for resources that would have improved their children's outcomes. Participants agreed that school transition teams did accept input from parents and students about the programs; however, they also felt there was a lack of understanding and knowledge of ASD on the part of the school teams. Although participants agreed that it was possible to get certain services, for example, home programming, they unanimously felt that other, vital services such as social skills, individualization, and community partnerships were elusive.

Summary and Interpretation of the Results

This phenomenological study sought to describe the parent perspectives of transition programs completed by their adult children with ASD. The 12 parents who participated in the study were divided into two groups: seven individuals participated in one-on-one interviews and five participated in a focus group which met once. There was one alternate participant who took part in the focus group replacing a person who had to drop out at the last minute. The results of the interviews and focus group indicate that although parents could identify some practices in

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transition with which they were satisfied, more often they described deficits in programming.

These parents were active in their children's transition programming, attending all meetings. Their

districts often relied on the parents for ideas and connections for the children's transition programs.

Participants were disappointed with deficits in knowledge of the school district personnel as it

related to the individual children, ASD, transition services, and community partners. They felt that

children should transition *to something*; for example, a continuation of the trainings and

internships students had been involved with during school. Parent participants strongly

encouraged development of social skills programs, community connections, and expanding

transition to begin when children are younger and end when they are older. All parents felt that the

more individualized the program, the better the outcomes for children.

In this study, I sought to determine parent perspectives of school transition programs and

how they prepared their children for life beyond school. The goal was to identify practices with

which they were satisfied and dissatisfied, as well as to seek their input about improving

programming. With the unemployment rate for individuals with ASD at 80% (Department of

Labor Statistics, 2016), it is important to improve their outcomes to reduce the burden on society

and families. Although there had been research about best practices in transition programs very

little information existed about outcomes. In addition, parents, who are the primary caregivers for

their children with disabilities, provide some insights which can lead to better transition

programming.

Findings Related to Parents of Adults with ASD's Perceptions of Transition Programs

The first issue identified was that parents each had their own definition of transition, and

none matched the IDEA definition. Some parent participants related their belief that district

personnel did not have a sufficient knowledge base to assist with transition. That may be a deficit

in the process that can be remediated through training of personnel. When meetings take place, school personnel could then be a resource for parents and students, beginning with an explanation of transition and what can be expected throughout the process.

At first, I thought I would be able to use the evidence-based practices identified by Test, Fowler et al., (2009): student focused planning, student development, family involvement, program structures, and community involvement, to discuss the experiences of the participants. Once I began to listen to the parents, I found it difficult to match their experiences with what the experts said should be happening. Many of the experiences of the participants lacked the particulars that had been determined to be effective. The outcomes for the children of the participants (see Appendices H - K) showed only three of the children were employed full-time and two were employed part-time. Their results were consistent with the data on employment from the Department of Labor.

Student focused planning, which was one of the best practices presented by Test, Fowler et al., (2009) requires an analysis of the likes and dislikes of the individual students as well as the strengths of the students (Rusch, Hughes, Agran, Marin, & Johnson; 2009; Lee & Carter, 2012; Rowe et al., 2015; Test, Fowler et al., 2009; Test, Mazzoti et al., 2009). In the 12 districts represented by the participants in this study, none of the students had engaged in interest inventories of any type. Parents indicated a need for not only determining the interests of their children, but their aptitude for jobs. One parent described her 6 feet 5 inch 250 pound plus son being placed in a china shop. This was not a good match and, in her opinion, did not advance his career goals in any way. Although school districts try to create the community partnerships necessary to improve experiences for children in transition, it proves to be difficult.

Another best practice identified as important was student development (Lee & Carter, 2012; Lindstrom, Doren, & Miesch, 2011; Nasamran, Witmer, & Los, 2017; Test, Smith, & Carter, 2014). As each transition program should be individualized, student development within them should also be based upon the strengths and weaknesses of the student. Participants in this study made many references to non-individualized planning in this area. One parent was told, "Children with disabilities don't take foreign language; they take study skills." There are instances where students do not need study skills, and in this particular instance, the parent had to have a special meeting to discuss his child's strength in study skills so the student would be allowed to take a foreign language. Another parent said the district tried to fit her child into a box, while others said their children were given courses that they had no interest in simply because they fit into the schedule. The professionals need to look beyond the obvious or convenient resources and placements to develop a broader spectrum of possibilities. If children are to succeed, they must be given the tools which they require.

Participants in this study were very involved with their children's education and transition programs. They participated in meetings and provided insights into their children's needs at those meetings. The literature supports family involvement as a best practice in transition (Anderson, Liang, & Lord, 2014; Fish, 2006; Kirby, 2016; Starr & Foy, 2012, Test, Fowler, 2009). The parents felt they had to be involved because when their children left secondary education, the family was their only support. One parent lamented, "Where would they be without us?" Parents and families are the only viable resources for students who have completed transition programs. This is an important question, for unless the individuals with ASD have support and interaction with family and friends, they are alone. There is a fine line of support and independence that the participants in the study continuously navigate.

As previously mentioned, community partnerships and involvement are an important part of transition programs (Test, Fowler et al., 2009). The literature review revealed several community-based programs which prepared individuals for life beyond school (Cimera, 2010; Moore-Gumora, 2014; Odom Duda et al., 2014; and Wehman et al., 2012) which is consistent with what participants seemed to be describing when they claimed that children should transition "to something." This idea is reflective of the apprenticeship programs in plumbing, electrical, and culinary, that many school districts have removed from their programming. Parent participants discussed "vocational" training where students can actually learn a trade or on the job training as better options to the current transition programming in schools.

All of the participants in this study cited social skills as an important aspect of life for their children; yet, none of the programs, which were provided by twelve different districts, provided social skills training. One participant, who was the parent of twins with ASD, explained that her child with lower skills received social skills training but her child who was in general education classes could not access the same support. This confirmed my expectation that fewer services were provided to students who were thought to be more typically functioning. Another participant also reflected on this, stating that her district said they did not have social skills programs. Many parents shared instances where their children could not read body language or understand sarcasm which lead to bullying and physical altercations. Although all individuals with ASD have deficits in social functioning at varying degrees, the districts involved with the participants in this study did not provide support in that area to these high functioning individuals.

One topic which continually came up was "disclosure." One parent discussed the dilemma of whether to speak to prospective employers, without her child's knowledge, about the disability, or let her daughter navigate on her own. On one hand, the prospective employer could be

sympathetic or not want anything to do with the issue. On the other hand, her experience was that her daughter would be misunderstood and lose the job anyway. Another parent interjected that his child would never speak to him again if he violated his confidence in that way. This is certainly a problem that could be addressed in transition planning as a part of preparing the individuals for life beyond school.

Limitations of the Study

This phenomenological study was limited by the recollections of the participants. The unique experiences of the participants were completed already; therefore, the impact of time on memory may have had an effect on the responses to questions. According to Creswell (2013) the qualitative research process is emergent; it is always changing to use the best methods to obtain the information. I used a self-designed list of interview and focus group questions intended to elicit information to answer the primary research question.

One limiting factor which could affect the study is the concept of reflexivity, or as Creswell (2013) explained, the author must convey her own personal relationship in the study. As the parent of an adult child with Level 1 ASD who has completed the transition process, I acknowledged a perspective on this topic. Although I have had these experiences, through the process of bracketing and member checks, I kept my feelings in check and reported the experiences of the participants only.

The survey instruments: the Qualtrics survey, interview, and focus group questions also limited the scope of the study. I focused the questions on participant satisfaction and dissatisfaction, as well as suggestions. The tools did not investigate the specifics of the transition documents; however, the outcomes and experiences speak for themselves.

Theoretical Implications

      This phenomenological study was based upon the work of theorists: Bronfenbrenner (1979), Freire (2000), and Mezirow (1991). Bronfenbrenner's theory describing the continually changing interactions between a person and others is seen in the constantly changing relationships between the parents and their children, spouses, school districts, and community support personnel. The more developed these relationships become, the more the individual parents can learn and add to their experiences. As the parents are adults, Mezirow's transformative learning theory applies to them. When the personal interviews and focus group began, participants were asked to recall a time which had passed, when their children were involved in school transition programs. Their recollections of the goals of the program prior to implementation and completion can be seen as their prior assumptions taken from their world experiences (Mezirow, 1991). As they progressed through the study, the participants reviewed and reflected on their prior worldviews, and finally were able to provide insights into what they learned in the process and how they changed their perceptions. The same steps could be taken by child study teams and others involved with transition planning leading to transformations in the current programming.

      Freire's (1970) critical education theory composed of dialogue, praxis, and conscientization was also seen in this phenomenological study. Participants engaged in dialogue with the researcher during the interviews and other parents during the focus group, where they revealed the cultural and economic, if not the political, reality of their experience. Their reflection has created a view of the transition process through their own eyes and has also allowed participants to identify the limiting factors that they have experienced. Each of the individual participants had their own revelations throughout the process and not only took steps to change their situations, but offered ideas for how to change the process of transition.

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Implications of the Findings for Future Practice

Although the results may not be duplicated, the information gleaned from the participants may provide insight for those who follow. Parents discussed what they felt would have improved the outcomes for their children with the hope that their experiences could improve the outcome for themselves as well as future students and parents involved in transition planning. It is clear that the children of the participants in this study, with higher functioning ASD, were not afforded detailed transition plans to address their needs. The social skills deficits that plagued the children throughout school did not disappear because they graduated. Although post-school programming is beyond their control, school districts should begin to develop plans earlier for individuals with ASD to transition to post school. Those plans should take into account the interests as well as the aptitude of the individual learners and provide support for social skills deficits.

Transformation of Society

Since one symptom of ASD is difficulty changing and adapting, neurotypical individuals, those without ASD, should be the ones to adapt to individuals with ASD. In practice, it is a difficult job to change society. There are many organizations springing up to address the problem of unemployment of individuals with ASD. These groups often attempt to hire individuals with ASD who are high functioning in the area of technology or math. Unfortunately, not all individuals with ASD who are high functioning are savants in technology or math. In the area of disabilities and in particular ASD, society must put aside preconceptions and deal with each person as an individual.

Recommendations for Further Research

The data collected in this study can be the basis for further research studies. This study was limited to 12 individuals. Future research can be undertaken using a larger sample size from a

broader geographical area. A comparative study between programs for Level 1 ASD and other levels could inform parents and school personnel about needs and services at various levels. Although parents who participated in this study tried to prepare themselves and their children for transition and life beyond school, they seemed to be lacking a complete plan with realistic goals and objectives. Future research could address what appears to be a deficit in the knowledge base of the professionals who are charged with guiding individuals through the process. As with children with disabilities, we need to assess professionals' scope of knowledge to enhance the likelihood of success for students and families.

Conclusion

In this phenomenological study I examined the parent perspectives of school transition programs which had been completed by their adult children with ASD to determine the practices with which parents were satisfied or dissatisfied and to collect their suggestions for improvement of transition. I used researcher-created tools to collect data: a survey, interviews, and a focus group. Data were analyzed using Creswell's (2013) and Moustakas' (1994) method of coding, horizontalization, reduction, and clustering around themes before creating a description from the words of the participants.

Of the 12 participants in the study only three of their children were employed full time, a fact that is consistent with Department of Labor statistics for 2016. Although there are best practices identified as producing optimum results in school transition, the parents involved in this study felt the schools did not prepare their children for the reality of life beyond school including daily living, employment, and leisure activities. They wished their children had "transitioned to" something rather than "falling off a cliff" as one parent described graduation. The results of this

study can inform parents and professionals to create more individualized programs that meet the

needs of each student.

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Appendix A: Organization Agreement Letter

February 6, 2017

Dear Ms. Arcaro,

Based upon my review of your research proposal, Parent Perceptions of the Transition Programs Completed by Their Adult Children with ASD, I am happy to assist you in disseminating your research information to our membership. The goal is to help you in locating possible participants through ███████'s membership.

Individuals' participation in the study will be voluntary and at their own discretion. I confirm that I am authorized to approve research for ████████. I understand that the data collected will remain confidential and may not be provided to anyone outside of the research team.

Sincerely,

████████, President and Executive Director

Appendix B: Organization Agreement Letter

Hi Judith,
It was a pleasure speaking with you as well. I look forward to meeting you at the Transition Conference. Please feel free to let the committee know that ▮▮▮▮▮ offers an avenue for research recruitment for approved studies. Approval is based upon IRB approval and a basic clinical review of the study's methodology. A listing may then be purchased for $50 for 2 months on our website and in 2 e-blasts. Feel free to contact me if I can be of further assistance.
Kind regards,

▮▮▮▮

▮▮▮▮
Education & Training Director

Hi Judy,
Thank you for this information. Your research study is approved for recruitment through ▮▮▮▮. Please reach out to ▮▮▮▮ to discuss the language you'd like to use in the brief listing.

Thank you!
Kind regards,

▮▮▮▮

Appendix C: Letter of Introduction to the Study

You are invited to take part in a research study entitled, "Parent Perceptions of the Transition Programs Completed by Their Adult Children with ASD." As the parent or primary caregiver of an adult between the ages of 18 and 30 who has completed school transition, you are in a unique position to provide valuable information about the positive and negative aspects of that program. If you have ever said, "I wish we had done…" or "I am so happy that we did…" then you are the perfect person for this study.

This study is being completed by me, Judithanne Arcaro, a doctoral student from Concordia University, Portland, Oregon. As the parent of a 25 year old individual with ASD I certainly have had experience with transition. Through the study of parental transition experiences, it may be possible to determine commonalities which can lead to better outcomes and be used to improve transition programming for individuals with ASD.

The purpose of this study will be to describe the experience of the transition process from the perspective of the parents or primary caregivers of individuals with ASD.

Criteria for Participation:

The participants will be eligible for the study if they are:

1. the parent or primary caregiver of an individual with ASD between the ages of 18 and 30 years of age who

2. has been diagnosed with an autism spectrum disorder including: Asperger Syndrome, Pervasive Developmental Disability-Not Otherwise Specified, or High Functioning Autism, and

3. can provide evidence of the diagnosis and a copy of the IEP which contains the completed transition section.

What to expect

If you agree to participate in this research project you will be asked to:

1. Give consent to participate in the study by signing a consent form

2. Complete a short online survey (Required by Concordia University)

3. Participate in either a one to one interview or a focus group with four other parents or caregivers (approximately one hour)

4. Provide honest, thoughtful responses to questions such as:

    a. How do you define success?

    b. Talk about your expectations of transition.

    c. How well did the transition program prepare your child for life?

5. Review the transcript of your responses to check for accuracy.

Voluntary Nature of the Study:

This study is voluntary. I will respect your decision about whether to participate. If you do participate, you may choose to leave the study at any time.

Risks and Benefits of the Study:

Being in this type of study poses only those risks that you would experience in daily life: fatigue, stress, or upset. It will not pose a risk to your safety or well being. Results of this study may be useful in creating new transition programs that support individuals with ASD or providing new knowledge which can assist individuals with ASD in life. Personal benefits may include satisfaction in helping to provide information about the process of transition which may benefit others as well as you.

Payment:

No form of payment or gift will be provided by Concordia University or this student for participation in this study.

Privacy:

All information that you provide will be kept confidential. You will be provided a pseudonym for the duration of this study. Your personal information will not be used for any purpose outside of this study. The researcher will not use your name or any identifying information in any portion of the written report of this research study. Data will be kept secure in a locked file by Judithanne Arcaro.

Contact and Questions:

If you have any questions you may contact me, Judithanne Arcaro, at XXXXXXXX or email: XXXXXXXXX.

CONSENT FORM
Research Study Title: Parent Perspectives of the Transition Programs Completed by Their Adult Children with ASD
Principal Investigator: Judithanne F. Arcaro
Research Institution: Concordia University, Portland
Faculty Advisor: Christopher Maddox, Ph.D.

Purpose and what you will be doing:
The purpose of this survey is to study parent experiences of school transition programs to identify helpful and harmful procedures and improve transition programming for individuals with ASD as well as adult outcomes. We expect approximately 17 volunteers. No one will be paid to be in the study. We will begin enrollment on July 7, 2017 and end enrollment on July 28, 2017. To be in the study, you will need to be the parent or primary caregiver of an individual with ASD who is between 18 and 30 years of age and provide evidence of the diagnosis and a copy of the transition plan.

If you agree to participate in this research project you will be asked to complete a short online survey (Required by Concordia University), participate in either a one to one interview or a focus group with four other parents or caregivers (approximately one hour), provide responses to questions such as: How do you define success? Talk about your expectations of transition. How well did the transition program prepare your child for life? Finally, you will be asked to review the transcript of your responses to check for accuracy.

Doing these things should take less than two hours of your time.

Risks:
There are no risks to participating in this study other than providing your information. However, we will protect your information. Any personal information you provide will be coded so it cannot be linked to you. Any name or identifying information you give will be kept securely via electronic encryption or locked inside the personal file cabinet located in my home office. When we or any of our investigators look at the data, none of the data will have your name or identifying information. We will refer to your data with a code that only the principal investigator knows links to you. This way, your identifiable information will not be stored with the data. We will not identify you in any publication or report. Your information will be kept private at all times and then all study documents will be destroyed 3 years after we conclude this study.

Benefits:
Information you provide will help in creating new transition programs that support individuals with ASD or providing new knowledge which can assist individuals with ASD. You could benefit by feeling satisfaction in helping to provide information about the process of transition which may benefit others as well as you.

Confidentiality:
This information will not be distributed to any other agency and will be kept private and confidential. The only exception to this is if you tell us abuse or neglect that makes us seriously concerned for your immediate health and safety.

Right to Withdraw:
Your participation is greatly appreciated, but we acknowledge that the questions we are asking are personal in nature. You are free at any point to choose not to engage with or stop the study. You may skip any questions you do not wish to answer. This study is not required and there is no penalty for not participating. If at any time you experience a negative emotion from answering the questions, we will stop asking you questions.

Contact Information:
You will receive a copy of this consent form. If you have questions you can talk to or write the principal investigator, Judithanne F. Arcaro, at XXXXXXXXXXX. If you want to talk with a participant advocate other than the investigator, you can write or call the director of our institutional review board, Dr. OraLee Branch (email obranch@cu- portland.edu or call 503-493-6390).

Your Statement of Consent:
I have read the above information. I asked questions if I had them, and my questions were answered. I volunteer my consent for this study.

_____   _____
Participant Name   Date

_____   _____
Participant Signature   Date

_____   _____
Investigator Name   Date

_____   _____
Investigator Signature   Date

Investigator: Judithanne F. Arcaro; email: XXXXXXXXXXXX
c/o: Professor Christopher Maddox, Ph.D.;
Concordia University – Portland
2811 NE Holman Street, Portland, Oregon 97221

Appendix E: Interview Protocol

Thank you again for agreeing to participate in this research project. Please make yourself comfortable. I thought that we could chat before getting down to serious business. Let me introduce myself…(doctoral student, area of interest, reasons, what I hope to find out, why it is important)

These questions are designed to answer the primary research question:

What are the lived experiences of parents and primary caregivers of individuals with ASD who have completed a transition program from school to post school?

1. Since many people define things differently, I would like to have your definition of transition. Describe your understanding of school transition. What is it?

2. Remember back to the years of transition. What can you tell me about your experience of transition with your child? How did you feel at that time?

3. Describe what the transition program consisted of?

4. Think about the meetings you had during transition time, how were you included in the planning and decision making processes of transition?

5. Describe your child's post graduation experiences.

6. Talk about your expectations of transition.

7. Talk about your impressions of transition.

8. How successful do you think the transition program was in preparing your child for life beyond school?

9. In retrospect, what other components could have improved your child's outcomes?

10.   What changes would you have made in the program if you could go back?

Appendix F: Focus Group Protocol

Before we begin, I would like to thank each of you again for agreeing to participate in this research project. As a way to break the ice, I would like to start with each person providing a brief introduction. I will begin. My name is Judy Arcaro. I am a doctoral student at Concordia University conducting research on Parent Perspectives of school transition programs. I am also the parent of an adult son with ASD.

These questions are designed to answer the primary research question:

What are the lived experiences of parents and primary caregivers of individuals with ASD who have completed a transition program from school to post school?

1. Describe your initial goals for your child while they were in school and their current outcome.

2. Describe your experience of transition.

3. Talk about the things your child learned throughout the transition program.

4. How well did the transition program prepare your child for life?

5. What practices were included in the transition program?

6. With which practices were you most satisfied? Least?

7. What types of problems, if any did you encounter during transition?

8. What types of problems, if any, have you experienced since leaving school?

9. Could the process of transition have been changed in any way that would have helped to avoid these pitfalls?

Appendix G: Qualtrics Survey

1. What is your gender?

2. What is your ethnicity?

3. What is the gender of your adult child with ASD?

4. What is the ethnicity of your child with ASD?

5. What is the age of your child with ASD?

6. My child finished high school at the age of…   18   19   20   21

7. My child: (select the best answer)

    a. completed a 4 year college.

    b. attended but did not finish college.

    c. completed a 2 year college or trade school.

    d. attended but did not finish a 2 year college or trade school.

    e. works full time.

    f. works part-time.

    g. volunteers.

    h. other (describe)

8. What is your child's diagnosis?   Autism   Asperger Syndrome   PDD-NOS

    ASD   Other _____

9. My child is currently: still in school   unemployed   employed part-time

    employed full time

10. Our approximate family income is…   Below $50,000 $50,000 - $100,000

    Above $100,000

Appendix H: Current Age of Participants' Children

_____

Age	Number of Children
18	1
19	1
22	1
24	1
25	3
26	2
27	1
28	1
30	1

_____

Appendix I: School Transition Completion Age of Participants' Children

Age	Number of Children
18	7
19	1
20	1
21	4

Appendix J: Post Transition Education of Participants' Children

_____

Education	Number of Children
Completed 4 years of college	4
Attended but did not finish college	0
Completed 2 year college or trade school	1
Some college or trade school	1

_____

Appendix K: Work History of Participants' Children

_____

	Number of Children
Works Full Time	3
Works Part-Time	4
Unemployed	1
Still in school	2
Other	2

_____

The Concordia University Doctorate of Education Program is a collaborative community of scholar-practitioners, who seek to transform society by pursuing ethically-informed, rigorously-researched, inquiry-based projects that benefit professional, institutional, and local educational contexts. Each member of the community affirms throughout their program of study, adherence to the principles and standards outlined in the Concordia University Academic Integrity Policy. This policy states the following:

Statement of academic integrity.

As a member of the Concordia University community, I will neither engage in fraudulent or unauthorized behaviors in the presentation and completion of my work, nor will I provide unauthorized assistance to others.

Explanations:

What does "fraudulent" mean?

"Fraudulent" work is any material submitted for evaluation that is falsely or improperly presented as one's own. This includes, but is not limited to texts, graphics and other multi-media files appropriated from any source, including another individual, that are intentionally presented as all or part of a candidate's final work without full and complete documentation.

What is "unauthorized" assistance?

"Unauthorized assistance" refers to any support candidates solicit in the completion of their work, that has not been either explicitly specified as appropriate by the instructor, or any assistance that is understood in the class context as inappropriate. This can include, but is not limited to:

- Use of unauthorized notes or another's work during an online test
- Use of unauthorized notes or personal assistance in an online exam setting
- Inappropriate collaboration in preparation and/or completion of a project
- Unauthorized solicitation of professional resources for the completion of the work.

Statement of Original Work

I attest that:

1. I have read, understood, and complied with all aspects of the Concordia
   University- Portland Academic Integrity Policy during the development and
   writing of this dissertation.
2. *Where information and/or materials from outside sources has been used in the
   production of this dissertation, all information and/or materials from outside sources
   has been properly referenced and all permissions required for use of the information
   and/or materials have been obtained, in accordance with research standards outlined
   in the Publication Manual of The American Psychological Association*

Judithanne F. Arcaro

Digital Signature

Judithanne F. Arcaro

Name (Typed)

November 9, 2017

Date