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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

TRANSITION TO ADULthood FOR STUDENTS WITH SIGNIFICANT
DISABILITIES: CULTURALLY DIVERSE PARENT PERSPECTIVES

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Education

Kara Francine Halley

College of Education and Behavioral Sciences
School of Special Education
Program of Special Education

August, 2011

This Dissertation by: Kara Francine Halley
Entitled: *Transition to Adulthood for Students with Significant Disabilities:
Culturally Diverse Parent Perspectives*

has been approved as meeting the requirement for the Degree of Doctor of Education in
College of Education and Behavioral Sciences in School of Special Education, Program
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ABSTRACT

Halley, Kara F. *Transition to Adulthood for Students with Significant Disabilities: Culturally Diverse Parent Perspectives*. Published Doctor of Education dissertation, University of Northern Colorado, 2011.

Parent expectations have been acknowledged as powerful predictors of positive post-school outcomes for students with disabilities; however, recent research continues to report poor outcomes for students with significant disabilities who are culturally and linguistically diverse. In previous research, the need for parental involvement during the transition process has been established, and this need is even more critical for students who have significant support needs because it is likely that family members will be the primary caregivers throughout their lifetime. Unfortunately, the literature has failed to comprehensively address the experiences and perceptions of parents that represent both minority cultures and significant disabilities in the transition process. Thus, this study explored culturally diverse parental perspectives of and experiences with the transition services being provided to their children with significant disabilities.

Participants in this study included five culturally diverse families, each having a child with a significant disability who was receiving transition services through the public school system. The primary research question this study addressed was: What are the experiences and perspectives of parents who are culturally and linguistically diverse on the transition services being provided to their children with significant disabilities? Data were collected using multiple in-depth interviews with each family, observations

conducted in the family home, demographic sheets filled out by participants, and IEP document reviews. The data were analyzed using grounded theory methodology.

Responses indicated that participants viewed their children as reflections and extensions of themselves. Based on these views, participants identified goals and dreams for the future lives of their children with significant disabilities. Unfortunately, negative experiences within different systems, lack of resources, and lack of opportunities served as barriers to the achievement of these goals and dreams for their children. Participants felt the need to use specific strategies to overcome these barriers. The deeper understanding of the experiences and challenges faced by culturally diverse families of transition-age children with significant disabilities provided by this study indicates a need for further research in this area and reform of current educational and adult agency services.

ACKNOWLEDGMENTS

There are many individuals that I would like to thank for their support, encouragement, and guidance as I have gone through this journey. First, I would like to thank the families who allowed me into their lives and who shared their personal memories, dreams, and fears. I hope my work has done you justice by accurately reporting your experiences and insights. Please know that the information you have shared will help other families better navigate through the transition process with their sons and daughters.

I would like to express my deepest appreciation to my advisor and mentor, Dr. Lewis Jackson, for providing me with invaluable guidance and support throughout my doctoral program. You helped me see many ways to change the injustice in the world. I am so grateful that I had the opportunity to work with you.

I would also like to thank the other members of my doctoral committee, Dr. Kay Ferrell, Dr. John Luckner, and Dr. Madeline Milian. Dr. Ferrell, you have amazing editing skills, and I appreciate you helping me polish the final draft. Your words of encouragement kept me going through the tedious revision process. Dr. Luckner, thank you for your honest feedback. You helped me see that being a good writer and researcher takes a lot of practice. Dr. Milian, thank you for sharing your knowledge and enthusiasm for students who are culturally diverse and for introducing me to this line of research. To each of you, thank you for taking the time to help me through this long and difficult process and for never giving up on me.

Next, I would like to thank the other faculty members at the University of Northern Colorado that I had the opportunity to learn from and work with over these past several years. I have gained invaluable knowledge and experience from each of you. I am a better teacher, researcher, and professional because of your efforts.

My lifelong friends and fellow doctoral students have been invaluable sources of support, and I would like to extend a special thank you to them. Loana Mason has been with me from the beginning of this doctoral journey. Your friendship, support, encouragement, and advice has influenced my teaching, research, and professional endeavors more than you will ever know, thank you. Dr. Shawn Sweet-Piantoni made this journey brighter and lightened my load by reducing my stress. Thank you for always providing a much needed distraction. Dr. Michele Trujillo was always quick to provide words of encouragement. Thank you for reminding me why I decided to take this journey in the first place. To each of you, I am truly grateful for all that you have done for me and will cherish our friendships always.

Next, I would like to thank the ladies of Alpha Sigma Alpha sorority for providing me with a home away from home. I will always appreciate the bond and adventures that I have had with all of you.

To my friends and colleagues at Metro State College of Denver, thank you for your support and encouragement during the final stage of this journey. I could not have asked for a better group of professionals with whom to work. I am so happy that I found others who share my desire to create the best possible educational experiences for children with disabilities. I am honored to be a part of this great department.

To my parents and family, you are such tremendous blessings in my life. I could not have survived this journey without all of your love, support, prayers, and encouragement. Thank you for believing in me and for all that you have done to help me. Last but not least, a very special thank you goes to my boys, Wyatt and Ryder, who have been on every step of this journey with me. You are the joy of my life; your smiles and laughter have made this journey bearable. I love you and I am thankful for you every day!

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CHAPTER I

INTRODUCTION

Carlos's Transition Program

Carlos, an 18 year old, began his senior year with a plan in place for his transition into life after high school. Challenged by severe physical and cognitive disabilities, he has minimal use of his arms and hands, the inability to walk or to sit up independently, and delays in his expressive language. Although Carlos depends on others to support him throughout his daily routine, he has several strengths that will help him be successful in his transition to adult life. Carlos independently uses an electric wheelchair at school by activating a switch for control, but he is unable to use this chair at home due to the fact that his house and the family car are not wheelchair accessible. He communicates verbally with his family and service providers; however, unfamiliar people usually have trouble understanding him. In the past, assistive technology has been suggested for Carlos by his speech therapist, but his family has been hesitant to agree to allow this to be included in his plan.

Carlos reads between a kindergarten and first grade level and can identify some sight-word vocabulary. He can correctly complete single digit addition and subtraction problems and is able to use a calculator to figure purchases when his special education class goes to the local grocery store for weekly community-based instructional activities.

He has been learning to manage a monthly budget through a new specialized curriculum developed for students with severe cognitive disabilities that his school has recently purchased. Carlos is shy and does not have many friends, although he has expressed the desire to have more friends. He is an only child who lives with his mother, aunt, uncle, three cousins, and his maternal grandmother. His large extended family provides Carlos and his mother with a support system that they can rely on during times of need.

Carlos has attended a self-contained special education program in a regular high school, located 45 minutes away from his neighborhood school, for three years. During this time he was also mainstreamed into non-academic classes such as physical education, choir, and art. For the past year, he has participated in a community-based program for special education students in his school. Carlos's individualized transition plan (ITP) contains goals related to improving his mobility skills, participating in vocational training experiences on a variety of different job sites, exploring and identifying appropriate augmentative and alternative communication devices, and developing friendships. His special education teacher has involved him in the school's peer buddy program in which he participates in a variety of community-based activities, such as bowling and going to the movies.

Carlos's service providers have expressed their desire for him to attend a new transition program for students ages 18 and 21 who continue to qualify for special education services because they are on the path to earning an alternative diploma or certificate of completion. This transition program is located near his home at a local community college. It would allow Carlos to audit courses, receive paid work experience and training, and participate in many different social activities with his peers. In order for

Carlos to be accepted into this program, he will have to get to the community college without using the school district's transportation, identify and complete at least two job training experiences, and begin to utilize some form of assistive communication technology that can be easily understood by unfamiliar people. Although many members of his educational team feel like this program would provide valuable opportunities for him, Carlos's family does not seem to be supportive of this idea.

Introduction to the Problem

Carlos's program is an example of typical transition services provided to many students with significant disabilities (Inge & Moon, 2006; McDonnell & Hardman, 2010). While transition services provided to Carlos by his transition planning team may be seen as beneficial and as having the potential to lead to positive post-school outcomes, involvement and expectations of Carlos's family are taking a backseat to the involvement and expectations of professionals in this process. Discrepancies between family and school expectations and desires can only lead to the failure of this plan (Johnson & Rusch, 1993; Morningstar, Turnbull, & Turnbull, 1995; Trainor, Lindstrom, Simon-Burroughs, Martin, & McCray Sorrells, 2008).

In special education, transition from the school system to post-school life has become one of the most important areas of service for students with disabilities (Kohler & Field, 2003; Landmark, Ju, & Zhang, 2010). Focus on transition services has intensified due to data from state and national surveys showing poor post-school outcomes for students with disabilities (Johnson, Stodden, Emanuel, Luecking, & Mack, 2002; Wagner, Newman, Cameto, & Levine, 2005, 2006). During this period of transition from the school system to the adult world, critical decisions are discussed and made with

regard to post-secondary education, employment opportunities, post-school support systems, and living arrangements. Typically, transition from childhood to adulthood is evident through some kind of event, such as going to college, getting a job, and/or moving away from home. Deviations exist, but the common expectation for young adults without disabilities is independence at some point (Cobb & Alwell, 2009; Geenen, Powers, & Lopez-Vasquez, 2001; Test, Fowler et al., 2009; Test, Mazzotti et al., 2009). While this expectation is the same for some students with disabilities, expectations for students with more significant disabilities tends to emphasize the concept of continual support.

Changing Demographics

Despite the increasing role of transition services, not much is known regarding cultural differences in attitudes, viewpoints, and meanings associated with transition (Kim & Morningstar, 2005; Trainor et al., 2008). However, the concept of culture as a framework that influences our perspectives of the world, our beliefs, our values, and influences how we act and feel in particular situations is widely accepted (Magana, 1999; Neal, McCray, Webb-Johnson, & Bridgest, 2003). For students with disabilities, transition can be complicated when the customs and beliefs of a minority culture are involved (Blacher, 2001; Landmark, Zhang, & Montoya, 2007; Lehmann & Roberto, 1996). Although there is a good deal of literature in the area of transition, few studies have examined this period of life for students with significant disabilities who are also culturally and linguistically diverse.

Based on the increase of minority populations in the United States, it is more likely than ever before that one will work and live near people who have different

cultural backgrounds. The U.S. census data shows that between 1980 and 2000, minority populations grew 11 times faster than the majority population (U.S. Census Bureau, 2002, November). As demographics have changed, students from diverse cultural backgrounds have come to make up a large proportion of students in our school systems. According to the United States Department of Education (2002), the percentage of ethnically diverse students attending public school increased from 27% in 1980, to 39% in 2000. At this rate, students who are ethnically diverse are expected to make up approximately half of all school age children by the year 2020 (Gollnick & Chinn, 2009). In several cities and states across our country, children from ethnically diverse backgrounds make up the majority of students (Gollnick & Chinn, 2009; Lustig & Koester, 2010; National Center for Education Statistics, 2009). According to the Annual Report to Congress, 39% of the school-age students served under the Individuals with Disabilities Education Act (IDEA) were from a culturally diverse background in the 2003-2004 school year (U.S. Department of Education, 2005). In the 2007-2008 school year 43% of students served under IDEA were from a diverse population, which represents a 1% increase per year (U.S. Department of Education, 2009). Consequently, it is increasingly more likely that service providers who develop individual education plans (IEPs) and collaborate on transition planning teams will work with minority students and families.

Despite this growing diversity in cultural backgrounds, many legal mandates and transition components are based on European-American cultural beliefs regarding disability, optimal post-school outcomes, and how best to achieve these outcomes. These beliefs about disability and post-school outcomes are not necessarily shared by all

cultures, and thus, cultural conflicts are quite probable when service providers simply comply with transition mandates.

Bryan (1999) has pointed out four main characteristics of a society that lacks a multicultural perspective: individualism, achievement, verbal expression, and the nuclear family structure. Individualism and achievement place value on independence and personal competence, thereby possibly devaluing those from cultures that emphasize collectivism. Since individuals who can verbally communicate in an eloquent manner are viewed as more capable and confident, those from cultures that emphasize silence and internal meditation, or individuals who are shy and quiet, or people who are unable to verbally communicate, are often devalued. As defined by the dominant culture, the nuclear family structure consists of the father, mother, and unmarried children. Within this structure, the influence and contribution of extended relatives and close family friends may be minimized, and the ideas and expressions of children are given as much consideration as adults. This view of the family structure can devalue those from cultures that emphasize the involvement of extended family members and friends, and it can also devalue those from cultures that give less value to the input of children. According to deFur and Williams (2002),

These cultural issues are important because the very conversation that transition service providers seek to have about futures planning, self-determination, strengths and needs, and productive adult lives may contradict the expectations and experience of families with whom we wish to partner (p. 106).

While discrimination may be experienced by families throughout their children's time in public school, insensitivity to culture can become particularly apparent during the period of transition to adulthood. Although there is not a significant research base, existing studies show cultural differences in the way disability is viewed (Blacher, 2001;

Harry, 1992), the degree to which independence is valued (Chavira, Lopez, Blacher, & Shapiro, 2000; Geenen et al., 2001), and even how successful adults are characterized (Harkness, Super, & Keefer, 1992). These differences can impact the transition planning process. As Geenen and her colleagues (2001) note, “How one defines successful adulthood, the end goal of transition planning, is determined by culture-specific values and expectations about many important issues, such as work, community integration, role expectations, and social functioning” (p. 266).

Significance of Parent Involvement

Traditionally, special educators have focused their efforts on the students with disabilities, often expecting parents to simply go along with what they have prescribed for their children. In reality, the Education for All Handicapped Children Act (EHA) of 1975, now called the Individuals with Disabilities Education Act (P.L. 94-142), mandates more extensive parent involvement in the IEP and related special education program planning. Furthermore, the IDEA amendments of 1990, 1997, and 2004 continue to strengthen parent involvement in transition planning activities.

Studies have been conducted related to parent involvement and satisfaction with special education services. The literature confirms parent involvement as one of the most critical factors affecting successful transition of students with disabilities into adult life (Benz & Halpern, 1987; Brotherson, Berdine, & Sartini, 1993; Geenen et al., 2001; Grigal & Neubert, 2004; Sileo & Prater, 1998; Zhang & Benz, 2006). Parents influence their children through their own values and expectations about such issues as appropriate adult roles and levels of independence (Benz & Halpern, 1987; Brotherson et al., 1993; Lee & Wehmeyer, 2004). Transition plans that include input, preferences, and

information from parents are more likely to improve the quality of life of students with disabilities (McNair & Rusch, 1991).

Family involvement can be especially critical for parents who are culturally diverse because a positive relationship between families and schools can lead to cultural understanding that service providers often lack (Greene, 1996; Geenen et al., 2001; Sileo & Prater, 1998; Valenzuela & Martin, 2005). However, culturally diverse parents may perceive their involvement in different ways and may have to deal with unique barriers that lead to their lack of involvement in the educational planning process of their children. Some families may define gender roles and norm-related behaviors differently in the context of their cultural beliefs (Geenen et al., 2001; Landmark et al., 2007). Thus, understanding and acknowledging these differences is required to facilitate family participation in their children's transition program. Unfortunately, available data indicates that parents and family members are often pushed into passive roles when planning occurs (Garriott, Wandry, & Snyder, 2000; Salembier & Furney, 1997), and for culturally diverse families, this is even more true (deFur, Todd-Allen, & Getzel, 2001; Landmark et al., 2007; Lynch & Stein, 1987).

Statement of the Problem

When looking at the post-school outcomes for students with disabilities who are culturally and linguistically diverse, discrepancies become apparent. These students tend to have worse post-school outcomes than even those of their peers with disabilities who are not from a culturally diverse background (Geenen et al., 2001). The National Longitudinal Transition Study (NLTS) found that these students have more difficulty obtaining employment than those students with disabilities who are not from a culturally

diverse background (Blackorby & Wagner, 1996). Furthermore, when these students were employed, Blackorby and Wagner found that they earned significantly less than their co-workers who were not culturally diverse.

Another study found that adults with disabilities who are not from a diverse cultural background are 40% more likely to be employed than those who are culturally diverse (Yelin & Trupin, 1997). Also, it appears that individuals from minority groups do not have equal access to services through the Department of Vocational Rehabilitation. Those individuals who are not ethnically diverse are more likely to use vocational rehabilitation services, thus experiencing higher rates of employment and receiving more pay than cultural and linguistically diverse individuals (Atkins & Wright, 1980; National Council on Disability, 1993).

The most recent statistics continue to show lower employment rates, wages, and enrollment in postsecondary education programs for students with disabilities who are racially and ethnically diverse when compared to their Caucasian peers (Blackorby, Wagner, Knokey, & Levine, 2007; Wagner et al., 2005; 2006). Continued post-school outcomes such as these indicate that professionals in the field might be implementing a one size fits all philosophy when providing transition services to their students.

Purpose of the Study

It has been predicted that children in the United States who are ethnically diverse will increase to approximately one-half of the school-aged population by 2025 (Singh, 1996). More recent predictions indicate, that approximately 55% of the United States population will be ethnically diverse in the year 2050 (U.S. Census Bureau, 2009). Regardless of available data reporting the changes in school population demographics,

research investigating transition services has not followed this trend. Missing from this research are the voices and experiences of individuals who are culturally diverse. In addition to this gap, there has been minimal research focusing on students with more significant disabilities, especially those who are from diverse cultural backgrounds.

The aim of this study was to address, via qualitative methodologies, parental perspectives on transition services that are being provided to their children with significant disabilities who are also culturally and linguistically diverse. The need for this study was based on three existing circumstances. First, the most recent findings from the second wave of the National Longitudinal Transition Study's (NLTS-2) reported negative post-school outcomes for this population of students, and acknowledged parent expectations as leading to positive post-school outcomes. Second, studies have found comparatively less participation from culturally diverse parents in transition related activities (Garriott et al., 2000; Geenen et al., 2001; Salembier & Furney, 1997). Finally, as previously noted, the existing literature has failed to comprehensively address the experiences and perceptions of parents from minority cultures who also have children with significant disabilities receiving transition services.

Guiding Questions

The primary research question addressed in this study is: What are the experiences and perspectives of parents who are culturally and linguistically diverse on the transition services being provided to their children with significant disabilities?

The guiding questions that will be used to help answer this question are:

- Q1 What are the expectations of parents who are culturally and linguistically diverse regarding the post-school life of their children with significant disabilities?

- Q2 What stories do parents who are culturally and linguistically diverse tell that illustrate their feelings and experiences with the transition process of their children with significant disabilities?
- Q3 Are there concerns or barriers facing parents who are culturally and linguistically diverse regarding their involvement in the transition process of their children with significant disabilities?
- Q4 In relation to program documentation (e.g., IEP/ITP), are there discrepancies between parental expectations and parental descriptions of their children's service needs when these are compared with the expectations and the services provided by schools?

Significance of the Study

The findings of this qualitative study are anticipated to be of interest to several groups, including school transition personnel, special education teachers, school administrators, parents of children with disabilities, and teacher educators. Based on the experiences of families from culturally diverse backgrounds and the recognition of the importance of parent involvement in the transition process, the information gained from this study will inform service providers about challenges facing these families during the process of transition. Through a better understanding of the experiences of culturally diverse families during transition, specific strategies that enhance parent involvement and improve transition outcomes can be identified.

Such understandings may influence the methods used to inform families of the transition process and provide them with tools that will encourage and maintain their involvement. In addition, these findings have the potential to assist transition planning teams in understanding and determining possible explanations and appropriate actions when involvement of family members is not occurring. Furthermore, administrators and policy makers will have information on the effects of the transition process on culturally diverse families in their communities. This may lead to changes in practices that do not

take into account different cultural perspectives, thereby eliminating barriers to positive transition outcomes and promoting opportunities that will help students with significant disabilities reach their full potential.

Definition of Terms

An accurate interpretation of the following terms will contribute to the reader's overall understanding of this study:

Significant Disabilities - The Association for Persons with Severe Handicaps (TASH) has defined the condition of severe disabilities as follows:

Those people who require extensive ongoing support in one or more major life activities in order to participate in an integrated community and enjoy a quality of life similar to that available to all citizens. Support may be required for life activities such as mobility, communication, self-care, and learning as necessary for community living, employment, and self-sufficiency (TASH, 2000).

Typically, individuals with significant disabilities are those individuals who have been labeled as having a severe disability, including labels such as moderate, severe, or profound mental retardation, developmental disability, and multiple disabilities (Westling & Fox, 2000). For the purposes of this study the latter definition was utilized in the selection of participants.

Transition Services - Numerous definitions of transition can be found, particularly in regulations and policies outlined in federal, state, and local laws. However, it generally can be defined as the process during which students prepare for life after they leave the public school system (Blacher, 2001). This process focuses on the goal of helping students develop skills they will need and providing them with supports to be successful once they exit the school system (Rusch & Menchetti, 1988). Congress most recently defined transition services in the following way:

Transition services refer to 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 (Individuals with Disabilities Education Improvement Act Amendments of 2004, sec. 602).

Culturally and Linguistically Diverse - Families with diverse cultural

backgrounds can be defined differently according to whether there is a focus on ethnicity, culture, or race (Kim & Morningstar, 2005). Culturally and linguistically diverse backgrounds can “involve different languages, rich cultural traditions, and patterns of relationships within families and communities that generate important differences in values, perspectives, expectations, and practices” (Kim & Morningstar, 2005, p. 93). These often include people who are African Americans, Asian Americans/Pacific Islanders, Hispanic Americans, and Native Americans. Individuals from these backgrounds were used to create a pool of participants for this study.

Theory - In qualitative research, as well as in all social science, theory is used in four distinct ways (Schwandt, 2001). First, theory can be seen as tested experimental generalizations. Second, theory can be referred to as a systematic underlying explanation of an assorted array of social phenomena. Third, the term theory can refer to theoretical perspectives that help to frame and solve problems as well as to understand and explain

social reality. Fourth and finally, theory is used in “critical theory, which refers both to a way of theorizing [about research methodologies, particular phenomenon, and society at large] and to the product of that theorizing” (Schwandt, 2001, p. 252).

Traditional uses of theory, which are the first two described above, are less likely to take into account the individual’s perspectives and experiences of the world. Moreover, in traditional inquiry, “the theorist is disinterested and views theorizing as an activity that takes place alongside all the other activities that comprise social life but has no immediately clear connection to those activities” (Schwandt, 2001, p. 253). In this way of thinking, theory then is applied to practice in a step that is separate from the research process.

In this study, the latter two of the four uses of theory were employed. *Critical theory* was used as the driving force behind this research model and paradigm (Creswell, 1998; Crotty, 1998). In using critical theory, the perspective that reality is socially constructed, and thus, that theory should not be separated from the context in which it is being constructed, was applied. Put differently, this study involved deconstructing the layers of context that have shaped the way culturally diverse parents perceive the transition process and the expectations they have for their children once they enter adulthood.

In addition to critical theory, a *grounded theory* approach was also applied in this study. In contrast to traditional uses of theory, grounded theory requires the researcher to conduct research and develop theory simultaneously. This methodology “generates an abstract analytical schema of a phenomenon, a theory that explains some action, interaction, or process” (Creswell, 1998, p. 241). The purpose of this approach is not to

validate a theory but to create a theory grounded in the research. In this process, the researcher may start with a theory he or she wants to adapt to a specific situation, or he or she may have no theory initially driving his or her work. “In either case, an inductive model of theory development is at work here, and the process is one of generating or discovering a theory grounded in views from participants in the field” (Creswell, 1998, p. 241).

Summary

The purpose of this study was to explore the perspectives of parents who are culturally and linguistically diverse on the transition process of their sons or daughters with significant disabilities. Although family involvement in the transition process is mandated, this does not fully occur for a variety of reasons for families who are culturally and linguistically diverse. For students like Carlos, as well as their parents and service providers, the findings from this study may serve as a starting point for important discussions that will lead to more productive partnerships.

The literature review contained within Chapter II examines the history of the transition movement and best practices in transition services according to leaders in the field of special education. It also offers a thorough examination of promising practices that relate directly to students with more significant disabilities, pertinent literature related to conflicts between cultural perspectives and transition mandates and practices, and a summary of previous research conducted on the transition program experiences of families and students with disabilities who are culturally and linguistically diverse. Finally, the use of qualitative research methodologies and the role of the researcher are discussed.

CHAPTER II

REVIEW OF LITERATURE

Literature reviews inform a study and provide a foundation from which questions can be investigated (Merriam, 1998). To provide a framework for this study, a literature review was completed on the history of the transition movement and best practices in transition services that have emerged from history and research as well as key components that pertain to students with more significant disabilities. This chapter will also focus on pertinent literature related to conflicts between cultural perspectives and transition mandates and a summary of previous research conducted on the involvement of families who are culturally and linguistically diverse during their children's transition out of the school system and into adult life. Finally, this chapter will conclude with a discussion of qualitative research, an explanation of the role of the researcher in qualitative inquiry, and my relationship to this research topic.

History of Transition Movement

It is important to discuss the evolution of transition services in order to gain a better understanding of how these services are currently being implemented. In the 1940s, discussions of educational programs for students with disabilities indicated that they were based on the principles of opportunity and proof (Duncan, 1943; Hungerford, 1941). These principles implied that all students could have the opportunity to attend classes open to other students; however, they had to demonstrate progress in order to remain in

the program. Educational opportunities of the time were, for the most part, unrestricted except to those students who were described as having a severe disability (i.e., sensory, physical, mental, or cognitive disabilities). These students, who resided largely in institutional environments, received little to no education or training and were exposed to excessive levels of isolation, neglect, and abuse (Blatt & Kaplan, 1966). Self-contained classes and special schools attended by students with disabilities not placed in institutions began to emerge in the 1950s, and for the next two decades students with mild disabilities had access to some type of educational program.

The concept of transition as a way to describe secondary programs is of fairly recent origin. However, many historical events have influenced the evolution of transition services, including: education and disability legislation; investment in the development of services; and research on effective practices. Halpern (1991) described three specific transition movements in which these historical events can be categorized: (a) the 1960s' cooperative work-study movement; (b) the 1970s' career education movement; and (c) the 1980s' and 1990s' transition movement. In addition to these three, the independent living movement can be viewed as a forerunner.

Although the aforementioned movements did not directly affect services being provided to students with significant disabilities in their time, they have had an influence on current practices. These four movements will be discussed in detail below and, finally, this section will end with a discussion of contemporary transition practices and current legislation.

The Cooperative Work-Study Movement

From initial efforts, it has been documented that curricula typically used with students without disabilities did not help some students with disabilities become independent, productive adults. However, this was also true of most segregated education programs due to their emphasis on meaningless activities and lack of rigor. Criticism of special education programs (Dunn, 1968; Johnson, 1962) led teachers to reject these practices and concentrate their efforts on preparing students for employment. During the 1960s, work-study programs emerged to address these issues, implemented jointly by local school districts and state rehabilitation agencies (Kolstoe & Frey, 1965). Data on vocational performance during this time revealed the remarkable success of these programs (Chaffin, Spellman, Regan, & Davison, 1971; Dinger, 1961; Findley, 1967). However, these studies often lacked rigor in their methodologies, and they were exclusively conducted on people with learning disabilities or behavioral disorders (Butler & Browning, 1974).

Criticisms of secondary work-study programs eventually began to surface in the 1970s. Brolin and Kolstoe (1978) found that training efforts during this movement were restricted to only a few types of jobs and they excluded people with sensory, physical, mental and cognitive disabilities from all but the most low skill entry level jobs. Clark and Oliverson (1973) also reported that special education teachers were providing the instruction to students with disabilities in academics and in vocational and independent living, and they were coordinating job placement and conducting follow-up supervision, but they were not necessarily trained in providing these services. On the other hand,

vocational educators were qualified to provide employment skills instruction; however, they often refused to work with students who had disabilities.

In response to these concerns, Congress passed the Vocational Education Act of 1963, giving students with disabilities the right to participate in vocational education along with students without disabilities. Unfortunately, the 1963 Act was not adequately funded and as a result, few students with disabilities were served in work-study programs. In an effort to change this, Congress passed Amendments to the Vocational Education Act in 1968 which set aside 10% of vocational education funds to serve students with disabilities. Based on these amendments, state departments of education and state vocational rehabilitation agencies were expected to work together through school districts to provide and fund work-study programs (Chaffin et al., 1971).

Unfortunately, large percentages of these funds were not used by many states. It was not until PL 94-142, EHA, was implemented in 1975 that some level of force could be used to control this situation. However, the expected results of these funds did not always occur because educational agencies were immersed in implementing PL 94-142 in their schools, and Vocational Rehabilitation began withdrawing from school cooperative programs. Despite the fact that the cooperative work-study movement had little impact on the services being provided to individuals with significant disabilities at that time, the stage was set for changes to occur later. For example, beginning in the early 1970s, Gold (1972, 1973) established that even individuals seen as the lowest-functioning in sheltered workshops could complete multifaceted assembly tasks with instruction.

The Career Education Movement

The narrow job preparation approach of work-study programs was replaced with the career education movement of the 1970s. Beginning as a general education movement, it was seen as not only preparation for employment but as a way to learn about all aspects of life (Marland, 1971). This movement affected not only students in secondary settings but also applied to students in elementary grades. Many career education models were developed during this movement. For example, one model based on Marland's earlier work, *The School-Based Career Development & Training Education Model* (Goldhammer & Taylor, 1972), defined career education for students with disabilities as education that focuses on the roles a person is likely to play in his or her lifetime. These might incorporate such roles as family member, student, employee, and citizen. This model provided a conceptual basis for our current thinking about career development, transition education, and transition services delivery (Brolin & D'Alonzo, 1979).

Although career education models impacted services for persons with mild disabilities, programs developed for individuals with significant disabilities continued to focus on preparing them to function in segregated environments. Accepted educational practices during this time for these students were based on the developmental learning theory (Super, 1957). According to this theory, instruction and curriculum provided to students with severe disabilities should match their developmental age level.

So for example, a student whose developmental age was measured at 6 months would be engaged in activities . . . [such as: object permanence, making babbling sounds, and mimicry]. Then, as students mastered one skill, the next one in the sequence of typical developmental milestones would be taught. This model would apply to students with disabilities who were 6 months old, 6 years old, or 19 years old (Schuh, Tashie, Lamb, Bang, & Jorgensen, 1998, p. 211).

Segregated programs designed for these students resembled early childhood programs and enrolled only students who were considered to have the same developmental levels (Calculator & Jorgensen, 1994).

The career education movement did eventually begin to impact services for students with significant disabilities. For example, Nirje (1970) developed the principle of normalization and recommended practices to apply this idea to the lives of individuals with more severe disabilities. This concept stipulated that people with disabilities have access to the same opportunities and environments as typical citizens, which eventually raised expectations for individuals with significant disabilities and led to their placement in typical community settings instead of segregated institutions or hospital settings. Furthermore, The Criterion of Ultimate Functioning (Brown, Nietupski, & Hamre-Nietupski, 1976) redirected the types of educational services provided to students with significant disabilities. This was a radical shift to a functional skills curriculum whose focus was teaching vocational and independent living skills, from a developmental curriculum, which had failed to prepare students with severe disabilities for the demands of adult life. Although these students still spent their entire day with other students who had severe disabilities, this approach was significantly better than the developmental model.

Independent Living Movement

At about the same time as the career education movement, the independent living movement began as a disability rights movement in the early 1970s by individuals with severe physical disabilities in reaction to years of policies that failed to provide them with meaningful services, supports, and access (DeJong, 1983). For example, vocational

rehabilitation agencies were required by federal policy to provide services only to those for whom there was a reasonable expectation that services would result in employment. The Rehabilitation Act of 1973 did make a commitment to provide services to people with disabilities who needed more assistance; however, rehabilitation personnel continued to serve only those people with general physical or sensory disabilities.

This movement helped to forward the deinstitutionalization and relocation of individuals with more severe disabilities into community residences. Although simply changing residence did not assure immediate improvement in quality of life, it was a major step forward in establishing a need for more community services, which transition would come to fill.

The Transition Movement

The transition movement, which moved career education into the current transition programs and services offered today, began with the Office of Special Education and Rehabilitative Services (OSERS) Transition Bridges Model (Will, 1984). This model emphasized the need to prepare students with disabilities for employment. One year later, Halpern's Transition Model (1985) expanded the OSERS Model by adding two non-vocational dimensions of adulthood: residential environments and social/interpersonal networks. In its current usage, the transition concept now includes such issues as employment, post-secondary education and training, independent living, community participation, leisure, health, financial/money management, and social/interpersonal skills (Patton & Dunn, 1998).

Several state and national studies influenced this shift in transition service delivery (Sitlington & Frank, 1990; Wehman, Kregel, & Seyfarth, 1985); however, the

majority of these early follow-up and follow-along studies focused on students with high incidence disabilities. Findings from the National Longitudinal Transition Study (NLTS) (Wagner, Blackorby, Cameto, Hebbeler, & Newman, 1993), mandated in 1983 by the Office of Special Education Programs (OSEP), has had a direct bearing on current issues of transition services for all students with disabilities. The NLTS-2 began in 2001 and ran through 2010. These studies have provided us with information on the post-school outcomes of students with disabilities and show how transition services are directly impacting the lives of students with disabilities.

Contemporary Transition Services and Current Legislation

Prior to 1990, many states provided varying degrees of transition services. These services differed in the extent to which they addressed various components of adult life. In addition, these services varied across states in relation to adequacy of coverage for persons with different disabilities. However, these discrepancies in services ended with the passage of the IDEA Amendments of 1990. Transition services, for the first time, were mandated for all students eligible for special education services. This law defined transition services as, “A coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities . . .” (IDEA 1990, PL 101-476, 20 U.S.C. Chapter 33, Section 1401(a)(19)). It also stated that the students’ Individual Education Plan (IEP) must include statements of needed services in the area of transition by the time they turn 16 years of age. In 1997, IDEA was reauthorized and additional changes were instituted. One important change was that the transition process was now to begin at the earlier age of 14. It also stressed the importance of considering students’ preferences and interests. With the

reauthorization of IDEA 1997, emphasis was placed on greater access to general education curriculum and assessment systems.

Around the same time period standards-based reform was getting underway. Reform efforts focused on raising academic standards for all students, holding schools accountable when students did not improve performance, and instituting state and district assessments (National Commission on Excellence in Education, 1983). The No Child Left Behind Act of 2001 continued this reform. Transition services mandated in IDEA 1990 and 1997 have had to compete with mandates to raise academic standards. As a result, transition specialists have stated that transition services must be integrated within the standards-based movement to ensure provision of transition services that do not impede academic achievement (Johnson et al., 2002; Kochhar-Bryant & Bassett, 2002).

Congress most recently passed the IDEA Amendments of 2004. One of the main changes implemented with this reauthorization relates to the re-definition of transition from a “goal-oriented” process to a “results-oriented” process that emphasized the need to follow-up with students to assess their post-school outcomes. Another change was moving the age to begin transition planning back up to 16 years. The reasoning behind this change was to ensure that students with disabilities are receiving access to their academic courses during the first two years of high school (Turnbull, Huerta, & Stowe, 2006).

Legislative mandates and investments in the development of transition services have created the framework for students with disabilities to participate in various academic, employment, and transition programs. Quality indicators, promising practices, and the organization of transition services have been investigated in an effort to identify

effective and valid programming in this area of service. In the next section, research regarding best practices in the area of transition will be discussed.

Best Practices in Transition Services

Many scholars have revealed practices believed to be effective in the transition process for improving students' post-school outcomes. In the 1980s, studies investigating promising practices in this area established criteria for model transition services. However, Kohler (1993) discovered that not all of these criteria were supported by evidence-based research. The problem with defining best practices in this area is that "transition planning means different things to different people" (Kohler, 1998, p.180). Some define transition as a process of linking traditional academics, remediation, and employment training to support successful post-school outcomes for students with disabilities, whereas others view it as restructuring the educational system for all students (Stodden, & Leake, 1994). Clearly identifying principles of best practice from transition research can, therefore, be hampered by differing definitions of transition.

Kohler's meta-analysis (1993) is the most widely accepted piece of research used for the identification of best practices in transition services. "The purpose of this study was to determine which transition practices have been identified or supported in the literature as having a positive impact on student outcomes" (Kohler, 1993, p. 107). Kohler's initial criteria included only evidence based strategies. However, Kohler found a dearth of this type of research pertaining to transition practices in the literature. This search resulted in a total of 47 articles consisting of 18 quasi-experimental studies, 18 follow-up studies designed to identify correlation between post-school outcomes and educational services, and 11 practitioner based articles consisting of suggestions for

effective transition practices. Despite these limitations, collective findings indicated that employment training, family involvement, and collaboration among agencies were cited as best practices in over 50% of the reviewed articles. Furthermore, social skills training, paid employment, and individual transition planning were supported as best practices in at least one-third of the articles.

Kohler (1996) later developed the *Taxonomy for Transition Programming*, which outlines practices associated with improving post-school outcomes for students with disabilities. It was developed as an outcome of several projects seeking to identify best practices in transition services that are supported with evidence-based research (Kohler, 1993), an examination of the very best transition programs (Kohler, DeStefano, Wermuth, Grayson, & McGinty, 1994), and the analysis of model transition program outcomes and activities (Rusch, Kohler, & Hughes, 1992). Using a process of concept mapping, the practices identified as being effective were organized into five main categories and several subcategories (Kohler, 1996). These categories included student-focused planning, student development, interagency collaboration, family involvement, and program structure. Subsequent research conducted in the area of transition services continues to support these five categories (Alwell & Cobb, 2006a, 2006b; Cobb & Alwell, 2009; Kohler & Chapman, 1999; Test, Fowler et al., 2009; Test, Mazzotti et al., 2009).

Student-Focused Planning

Student-focused planning refers to practices that facilitate student self-determination and applying assessments to gather information to develop individual education programs (Kohler, 1996). This category includes three subcategories: IEP

development, student participation, and planning strategies. “An important aspect of student-focused planning is that educational decisions are based on students’ goals, visions, and interests” (Kohler & Field, 2003, p. 176). Therefore, it is important to help students identify their preferences and interests through opportunities that develop self-awareness and to use this information in the creation of educational goals and objectives that result in more appropriate and meaningful IEPs.

Another essential aspect of student-focused planning is the participation of the student in the transition planning process. In order to ensure active participation in the process, “students must exercise self-advocacy skills to express their self-awareness to others” (Kohler & Field, 2003, p. 177). Physical presence of students at their transition planning meeting is not sufficient. They need to be the driving force behind the planning process and during the meeting.

A variety of planning strategies have been developed in order to ensure that transition planning is student and family centered, that student interests and preferences are documented, and that students demonstrate self-determination within the planning process (Test, Mason et al., 2004). For example, the Self-Directed IEP Model was found to be helpful when training students to lead and participate in their IEP meetings (Allen, Smith, Test, Flowers, & Wood, 2001; Cross, Cooke, Wood, & Test, 1999; German, Martin, Marshall, & Sale, 2000; Martin et al., 2006). Students who had received training in the Self-Advocacy Strategy, another model, were able to more fully participate in their IEP meetings by identifying more goals and contributing more information (Hammer, 2004; Lancaster, Schumaker, & Deshler, 2002; Test & Neale, 2004; Van Reusen & Bos, 1994; Van Reusen, Deshler, & Schumaker, 1989).

Student Development

Student development refers to the acquisition of functional living and work-related skills through school- and community-based training opportunities (Kohler, 1996). This category includes six different subcategories: structured work experience, employment skills instruction, career and occupational curricula, life skills instruction, assessment, and support services. Through these activities, skills are developed and applied that lead to positive post-school outcomes (Alwell & Cobb, 2006b; Alwell & Cobb, 2007; Blackorby & Wagner, 1996; Heal & Rusch, 1995; Wehmeyer & Schwartz, 1997; Xin, Grasso, Dipipi-Hoy, & Jitendra, 2005). “To help students achieve the maximum benefit and generalize their skills to multiple environments, these experiences are provided in both school-based and community-based settings, including work-based situations” (Kohler & Field, 2003, p. 177). It is important for needed supports and accommodations to be identified in school and the community so students are able to be more successful in these environments.

Student development practices aimed at preparing students with disabilities to function successfully and independently in adulthood continue to be supported by research. Several studies have found that work experiences and job placement are essential to successful transition (Kohler, 1993; Kohler et al., 1994; Mechling & Ortega-Hurndon, 2007; Rusch & DeStefano, 1989; Rusch & Millar, 1998; Wehman, 1990; White & Weiner, 2004). One study found that besides work experience, students also need academic instruction, social skills training, preparation in job seeking skills, and continued support after they exit the school system in order to improve employment outcomes (Benz, Yovanoff, & Doren, 1997). According to Benz, Lindstrom, and

Yovanoff (2000), work-related experience and student-identification of post-school goals were strongly correlated with higher graduation and employment rates. Colley and Jamison (1998) found that work-related experience, career education, and mainstream academics were associated with higher employment rates.

Farley and Johnson (1999) explained specific strategies for increasing students' abilities to make decisions, identify career options, and find employment, which are all central to vocational preparedness. According to several studies, comprehensive vocational assessment has also been shown to be effective (Hughes et al., 1997; Kohler et al., 1994). Vocational assessment should be completed with every student in order to identify both areas of concern and areas in which the students show competence and proficiency in order to make a more meaningful transition plan. Social skills training has also been identified as an important practice needed by many students with disabilities (Alwell & Cobb, 2007). Studies have shown that many people with disabilities demonstrate ineffective social skills which lead to unemployment, social isolation, and an inability to have a full, productive life after they leave the school system (Clark & Klostoe, 1995; Hughes et al., 1997; Kohler, 1993; Kohler et al., 1994).

Integrated activities in the school and community are a vital part of the transition process (Bates, Cuvo, Miner, & Korabek, 2001; Cihak, Alberto, Kessler, & Taber, 2004; Halpern, Lindstrom, Benz, & Nelson, 1991; Hughes et al., 1997; Kohler et al., 1994; Wehman, 1990). Students with disabilities will prosper from experiences that are provided in real life contexts. They will be more likely to acquire knowledge and skills needed to function in different settings if they have the opportunities to learn and practices in those settings.

Interagency Collaboration

Interagency collaboration focuses on the involvement of local businesses, community organizations, and adult agencies in all areas of transition planning and services (Kohler, 1996). Agreements between agencies that specifically define roles, responsibilities, approaches to communication, and other collaboration strategies that improve instruction practices and program development promote successful interagency collaboration (Benz, Johnson, Mikkelsen, & Lindstrom, 1995; Blalock, 1996). This category includes only two subcategories: collaborative service delivery and collaborative framework. “The purpose of these collaborative activities is to implement an integrated system that addresses the lifelong learning and support needs of a community’s members” (Kohler & Field, 2003, p. 178).

Interagency collaboration, including business partnerships, is a must according to several scholars (Clark & Klostoe, 1995; Halpern et al., 1991; Izzo, Cartledge, Miller, Growicki, & Rutkowski, 2000; Repetto, Webb, Garvan, & Washington, 2002; Rusch & Millar, 1998; Wehman, 1990). Adult services providers are key players in the transition process. Efforts must be ongoing to improve coordination of various agencies and school-based transition services. Devlieger and Trach (1999) concluded that interagency collaboration is an important factor that facilitates achievement of transition goals.

The Community Transition Team Model (Halpern, 1985) was found to be successful in increasing school and community capacity to better support students with disabilities. Benz, Johnson, Mikkelsen, and Lindstrom (1995) found that unproductive planning meetings, intimidating language, and multifaceted procedures served as barriers to successful collaboration for several different stakeholders, including students

and their parents. Thus, breaking down such barriers would be an important goal of early collaboration efforts.

Family Involvement

Family involvement practices focus on the involvement of parents and family members in the transition planning process and service delivery. Training for families and activities leading to family empowerment increase their ability to work more effectively with service providers (Kohler, 1996). The category of family involvement includes three main subcategories: family involvement, family empowerment, and family training. For years, family networks and involvement have been seen as essential to the transition planning process according to several scholars in the field (Clark & Klostoe, 1995; Halpern et al., 1991; Hughes et al., 1997; Kohler, 1998; Kohler et al., 1994; Luft, 2008; Patton & Browder, 1988; Rusch & DeStefano, 1989; Rusch & Millar, 1998; Turnbull, Turnbull, Erwin, & Soodak, 2006; Wehman, 1990).

Active involvement of families is correlated with increased school attendance, lowered dropout rates, improved scores on assessments, decreased negative student behavior, and increased student self-esteem (Blackorby & Wagner, 1996; Falbo, Lein, & Amador, 2001; Flaxman & Inger, 1991; Gonzalez, 2002; Lehr, 2004). Furthermore, research has shown that family involvement is often critical for successful post-school outcomes for young adults with disabilities (Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; McNair & Rusch, 1991; Morningstar et al., 1995; Wagner et al., 2005). Although active parental involvement appears to make a significant difference in post-school outcomes of students with disabilities, recent studies have consistently indicated that most parents continue to play a passive role in transition planning regardless of

parental attendance at meetings (Garriott et al., 2000; Salembier & Furney, 1997; Smith, Gartin, Murdick, & Hilton, 2006; Steere, Rose, & Cavauiolo, 2007). Transition plans should involve families and be individualized to accommodate family and student values and preferences even if they conflict with those of school personnel.

Several suggestions to improved family involvement in the transition process have been prescribed. Benz, Johnson, Mikkelsen, and Lindstrom (1995) reported that parents wanted more informational materials on the transition process and available post-school supports. Additional suggestions included combined training for service providers and families, annual community resource fairs, and support groups and networking opportunities with other families going through the transition process. DeFur, Todd-Allen, and Getzel (2001) found an improvement in parental involvement during transition planning when more personal relationships with other members of their child's transition planning team existed. Furthermore, Morningstar and her colleagues (1995) indicated that increasing family involvement in the transition planning process and career development led to improved post-school employment outcomes.

Program Structure

Program structures are characteristics of a school system that promote effective transition focused instruction, planning, and service delivery, including expanded curricular options that incorporate community and outcomes-based education, sensitivity to cultural diversity, clearly stated values and mission, highly-qualified service providers, and adequate resource allocation (Kohler, 1996). This category includes six subcategories: program philosophy, program evaluation, strategic planning, program policy, human resource development, and resource allocation.

Several studies have researched effective transition practices and the implementation of IDEA mandates across different states and local school districts (Furney, Hasazi, & DeStefano, 1997; Hasazi, Furney, & DeStefano, 1999). Findings from these studies “reaffirmed the importance of program policies and philosophies as a foundation through which transition-focused education occurs” (Kohler & Field, 2003, p. 179). Furney, Hasazi, and DeStefano (1997) evaluated three states considered to have model transition programs and found evidence of the following practices: having a shared vision of transition services, straightforward approaches to policy implementation, utilization of effective collaboration strategies, and change efforts focused on current research. Hasazi, Furney, and DeStefano (1999) also found differences between effective transition programs and those programs demonstrating challenges and limitations. These differences revealed that effective transition programs included the following characteristics: person- and family-centered planning approaches, collaboration among agencies, systematic training and professional development, supportive leadership in the area of transition services, coordinated efforts to reform transition policies and procedures, and working relationships among different transition initiatives.

Collet-Klingenberg (1998) revealed several best practices, including the need for follow-up analysis of the effects of transition practices that monitors students’ progress beyond high school. Halpern (1999) also identified best practices in transition services, such as identification of resources for providing transition-focused instruction, improvement of service provider skills for implementing transition services and providing professionals with the opportunities to utilize their skills, and facilitate the replication of effective model programs.

Utilization of Best Practices

“The extent to which particular transition practices have been implemented varies widely” (Kohler & Field, 2003, p. 179). For example, Lehmann, Bassett, Sands, Spencer, and Gliner (1999), in their investigation of student involvement in the transition planning process, noted that “ironically, many basic transition elements, often presumed in our field already to exist (e.g., transition teams, student-focused planning, and basic curricula), were selected by schools participating in this study as targeted interventions” (p. 16). Likewise in the state of Ohio, McMahan and Baer (2001) concluded that school districts were complying with policy with some consistency; however, effective practices were not being implemented. Everson, Zhang, and Guillory (2001) also found similar results in Louisiana with their evaluation of 329 transition plans.

More empirical research needs to be conducted on transition practices because opinion-based practices are not enough when there is a limited amount of time in a student’s education experience. Educators need to capitalize on the time they have with the students by incorporating substantiated, or evidence-based, practices into their programs (Landmark et al., 2010, p. 173).

Implementation of best practices in transition services is not only mandated by law but is important because it affects the future lives of children with disabilities. While the foregoing discussion addresses transition practices for students with mostly high-incidence disabilities, many of these identified practices are also effective for students with significant disabilities; however, there are some differences. In the next section a discussion of how these practices relate to students with significant disabilities is presented.

Transition and Significant Disabilities

For students with the most severe disabilities, there is a lack of empirically-based research about which practices lead to positive post-school outcomes (Baer, McMahan, & Flexer, 2004; Braddock, Hemp, & Rizzolo, 2008; Grigal, Hart, & Migliore, 2011). Those practices intended for students with significant disabilities that are most often cited include the following categories: comprehensive transition planning and person-centered; secondary curricula, which include instruction in functional life skills; adult agency coordination; full family participation; and program structures and policies. These five categories of services parallel those described by Kohler (1996). As applied to significant disabilities these five categories of practices are described in detail in the subsections below. A final subsection summarizes these findings.

Comprehensive Transition Planning and Person-Centered

In regard to person-centered and comprehensive transition planning several studies support the practice of highly individualized and comprehensive transition planning (Agran & Hughes, 2008; Halpern et al., 1991; Hughes et al., 1997; Thoma & Wehman, 2010; Wehman, 1990). However, certain transition planning areas are often overlooked based on the function of a student's disability. For example, many times students with significant disabilities are not provided academic instruction based on the assumptions that they will not benefit from this type of programming in their life after high school or they will not be attending any postsecondary education programs (Grigal et al., 2011). Traditionally, these students attended high school until they were 21 years old, receiving mostly daily living instruction, and then they transitioned into a variety of adult services, such as, supported work, supported living, day treatment facilities, and

sheltered workshops (Agran, Snow, & Swaner, 1999; Certo, Pumpian, Fisher, Storey, & Smalley, 1997). However, a variety of ecological assessment procedures can now be used for designing more age-appropriate goals for students with significant disabilities during their academic years, so that access to content can be assured (Calculator & Jorgensen, 1994; McDonnell, 2010). Furthermore, post-secondary education programs designed for students with significant disabilities have begun to emerge (Doyle, 2003; Grigal, Neubert, & Moon, 2005; Grigal et al., 2011; Hafner, Moffatt, & Kisa, 2011).

Several studies support the use of self-determination and student participation in the transition planning process as best practice (Collet-Klingenberg, 1998; Halpern, 1999; Konrad, 2008; Wehman, 1990; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007). Traditionally, for most students with significant disabilities this has not always been viewed as possible. However, the student's IEP team is responsible for ensuring their involvement in the process as much as possible. Typical ways of conducting the transition planning process might need to be modified in order for some students to take an active role. The use of person-centered planning approaches results in educational and transitional plans built around the students' preferences, interests, and needs, and the individualized services that can be put into place for these students. Documentation of student preferences and interests for transition planning and goal setting in their transition plans is a legal mandate of IDEA. Many agree that all students with disabilities who participate in self-determination practices have better post-school outcomes (Agran & Hughes, 2008; Benz et al., 2000; Halpern, 1999; Thoma & Wehman, 2010; Wehman, 1990; Wehmeyer & Kelchner, 1995). Incorporating the practice of person-centered planning can ensure student involvement in the transition planning process (Miner &

Bates, 1997; Polychronis & McDonnell, 2010). Several person-centered planning approaches have been identified including: McGill Action Planning System (MAPS), Circle of Friends, Personal Futures Planning, lifestyle planning, essential lifestyle planning, and Planning Alternative Tomorrows with Hope (PATH) (Falvey, Forest, Pearpoint, & Rosenberg, 1993, Mount & Zwernik, 1988; O'Brien, 1987). While these approaches to planning are beneficial for all students with disabilities, this might be the only way some students with the most significant disabilities can be included in their transition planning.

Secondary Curriculum and Functional Life Skills

Similar to practices identified as promising for all students with disabilities, secondary curricula incorporating instruction in functional life skills, paid work training opportunities, and access to general education classes and environments are also suggested as best practices for students with significant disabilities (Downing & Peckham-Hardin, 2007; Hunt & McDonnell, 2007; Inge & Moon, 2006; Wagner et al., 2005; Wehman, Inge, Revell, & Brooke, 2007). Furthermore, several specialized curriculums have been developed for students with more severe disabilities as a spin-off from the transition education models of the 1980s and 1990s (Smith & Schloss, 1988; Wehman & Kregel, 2004). Traditionally, programming for secondary students with significant disabilities have focused on work experiences and independent living instruction in community based and work based environments. In fact, for all students with disabilities, community based instruction and assessment is strongly recommended for providing meaningful learning opportunities (Blackorby & Wagner, 1996; Heal & Rusch, 1995; McDonnell & McGuire, 2007; Wehman, 2006; Wehmeyer & Schwartz,

1997). Consequently, this type of programming and use of specialized curriculums lead to limited opportunities for students with significant disabilities to participate in typical academic curricula and social activities in their neighborhood school with peers who do not have disabilities (Fisher & Sax, 1999; Inge & Moon, 2006). Furthermore, it has been demonstrated that community-based instruction occurring before the age of 18 or in place of more academic instruction causes students to miss out on many important experiences within their school community, thereby, pushing them further behind (Inge & Moon, 2006; McDonnell, Mathot-Buckner, & Ferguson, 1996; Schuh, Tashie, Lamb, Bang, & Jorgensen, 1998).

It has been recommended that both general and special education teachers collaborate to identify times in which functional skills training and instruction can be embedded in the general education curriculum and extracurricular activities (Schuh et al., 1998; Wallace, Anderson, & Bartholomay, 2002). Additionally, employment and on-the-job training activities can be facilitated in the same ways that these experiences are provided to peers without disabilities, such as having an after school and summer job. Practices like these are concerned with access to integrated classes and activities for high school students with significant disabilities, particularly when opportunities to socialize and communicate with same-age peers without disabilities are lacking (Carter & Kennedy, 2006; Hunt & McDonnell, 2007; McDonnell et al., 1996; Schuh et al., 1998; Tashie & Schuh, 1993). Accordingly, Halpern (1999) has identified several promising practices in transition services, one of which focuses on the need to integrate special education programs and transition services within the overall reform of general education.

Adult Agency Coordination

Students with disabilities, particularly those with significant disabilities, require a variety of services and supports once they leave the school setting (Hanley-Maxwell et al., 1998; Morningstar, Kleinhammer-Tramill, & Lattin, 1999; Steere et al., 2007). Interagency collaboration that develops services and supports is required for successful transition outcomes for students with significant disabilities (Inge & Moon, 2006; Noonan, Morningstar, & Gaumer Erickson, 2008; Wehman, 2010). Furthermore, federal regulations under IDEA address the importance of developing interagency linkages for students before they leave the school system. Linkages with postsecondary education, vocational rehabilitation, developmental services, or local adult service agencies, such as, supported employment or supported living providers, should be explored and actively arranged during the transition planning process. Without early and effective interagency collaboration, the student is likely to encounter barriers to obtaining services essential to the pursuit of future goals and aspirations after graduation from the public school system (Johnson et al., 2002; Morningstar et al., 1999). According to Wehman (1996), there were more than 186,000 people with disabilities awaiting some type of formal support, with the majority of them having severe disabilities. Another dilemma faced by those attempting to access formal programs arises when there are differences in eligibility criteria and policies from school to adult agencies. This has the potential to create situations in which a student who was previously receiving special education services may not be eligible for an adult program (Ferguson & Ferguson, 2001). As a result of limited resources in the adult services system, demands are placed on families to organize

personal and informal resources necessary to meet the needs of their adult children with disabilities.

Full Family Participation

Full family participation in the transition process, focusing on self-identified needs and concerns, is considered one of the most important transition practices (Kohler & Field, 2003). Although studies have found that parental involvement in this process increases positive post-school outcomes for students (Blackorby & Wagner, 1996; Blackorby et al., 2007; Wagner et al., 2005; 2006), family priorities continue to be undervalued in most educational planning activities (Salembier & Furney, 1997; Smith et al., 2006; Steineman, Morningstar, Bishop, & Turnbull, 1993). Turnbull and Turnbull (2001) reported that inadequate progress has been made in helping students with significant disabilities and their families achieve self-determination and in ensuring that family expectations are considered during the transition planning process. Full parental participation requires more than just simply signing off on their children's educational plans. For example, one study revealed that parents could assist in finding and creating job placements for their children with significant disabilities by utilizing a comprehensive interview process (Hutchins & Renzaglia, 1998). Another study showed that parental efforts more often resulted in integrated employment and post-secondary training opportunities, while agency efforts resulted in more sheltered employment for individuals with cognitive disabilities (Devlieger & Trach, 1999). Professionals need to recognize that family members may be the sole source of consistent support for individuals with disabilities, especially those with significant disabilities (Hanley-Maxwell et al., 1998;

Kim & Turnbull, 2004). Thus, it is critical that families participate in determining transition goals and post-school outcomes.

Program Structures and Policies

Program structures that allow for collaboration among agencies, transition policy development, transition resource allocation, evaluation of effective programs, and professional development for service providers and families are identified as essential in the transition of students with disabilities including those with significant disabilities. School systems and community agencies must take into account the needs of an ever-growing diverse group of students. Follow-up studies and program evaluation can provide feedback to schools and state and federal governments on the weak elements of curricula and instruction being provided to students with disabilities. Service providers must be sure that all students are involved in their pursuit of improving education and transition services. Transition planning is fundamental to the success of all students with disabilities, including those with the most significant disabilities. No longer is it acceptable to create a system for some students to the exclusion of others. We must come to the realization that the best way to prepare students to be successful, contributing members of society is to ensure they receive fully inclusive opportunities that respect and celebrate the diversity in our communities (Tashie, Malloy, & Lichtenstein, 1998).

Summary of Best Practices

In summary, it is important to follow the best possible practices that will lead students with significant disabilities to achieve their desired quality of life when they exit the school system. An essential best practice is the use of student-focused planning that incorporates person-centered planning approaches; opportunities to be self-determined;

and comprehensive planning, including ecological assessment procedures that take into account postsecondary options that have traditionally been denied to this particular population. In addition, transition services that adhere to best practices incorporate student development opportunities embedded within general education environments and curricular options that lead to instruction in functional life skills, social skills, and paid work training opportunities. Collaborative service delivery that takes into account the unique needs of students with significant disabilities and their families after they exit the school systems has also been identified as a vital component of the transition process. Furthermore, the importance of interventions and interactions that empower family members to be active members of their child's transition planning team are essential for program success. Finally, program structures focusing on the development of collective transition practices that can be used with all students are necessary for providing transition services that are not separate from a student's educational program.

Of these five categories of best practices, family involvement and participation is especially critical. After all, the families will most likely be involved with their children long after they leave the school system. The next section discusses family involvement in some detail, and also focuses on cultural considerations when providing transition services.

Family Involvement and Cultural Considerations

Regardless of the transition practices provided to students with disabilities, the majority of research has emphasized the need for, and impact of, family involvement on the success of transition planning. It is unlikely that the previously described best practices would happen effectively without the involvement and participation of the

students' families. Clearly, when family members have different beliefs and values than those of school personnel, many conflicting expectations can surface and can become barriers to effective family involvement. This section will discuss the family perspective on transition and possible barriers, the impact of cultural differences, considerations that should be taken into account when working with families who are culturally diverse, and finally, the cultural conflicts and barriers that can occur when transition practices are not culturally sensitive.

The Family Perspective

Transition to adulthood is a process not only affecting the student, but one that affects the family as a whole. Research on the factors influencing positive transition outcomes has supported the critical need for family involvement as mentioned previously (Kim & Turnbull, 2004; Kohler, 1998; Luft, 2008; McNair & Rusch, 1991; Morningstar et al., 1995; Turnbull, Turnbull et al., 2006). However, researchers indicate that actual parental participation in school-based transition planning diminishes during the transition period despite broad agreement regarding the importance of parent involvement (Geenen et al., 2001; Landmark et al., 2007; Smith et al., 2006).

McNair and Rusch (1991) found that although most parents wanted to participate in the decision making process, they were less involved in transition programming than they wanted to be because of lack of opportunity. Several other studies have revealed that parents who participated in the transition process were likely to have thought about a post-school plan for their child's adult life (Gallivan-Felon, 1994; Garriott et al., 2000; Hanley-Maxwell et al., 1998; Salembier & Furney, 1997).

Salembier and Furney (1997) studied parents' perspectives of their participation in the transition process and reported that most parents saw themselves involved in this planning process in a variety of different ways. Their findings showed that 69% of parents felt they were passive participants more than they contributed during the meeting, 28% felt they only contributed one or two times, and less than 10% felt they contributed to the meeting more than simply listening. Moreover, 30% of these parents felt dissatisfied with the transition planning process.

Likewise, Garriott, Wandry, and Snyder (2000) found that of the parents who participated in their children's IEP meetings all the time, 50% felt like they were there to receive information instead of provide information or make decisions about their children's program. Almost 26% felt dissatisfied with their involvement in the meeting. Parents who were dissatisfied said they felt their input was not valued, that other team members did not respect them, and that others were not accepting of them during this process.

In summary, research has supported the fact that family involvement is a critical factor affecting positive post-school outcomes. Many parents attended their children's transition planning meetings and wanted to be actively participating in the decision making process. However, studies have indicated that they do not feel like equal members of their children's transition planning team. Although federal mandates have pushed for increased parental involvement in the transition planning, it is evident from this research that families are not valued members of the decision making team.

Factors Affecting Family Involvement. In spite of the established importance of family participation, there are a number of barriers that have been described in the

literature. These include contextual barriers, bureaucratic barriers, and professional attitudes (Kim, 2006; Kim & Morningstar, 2005; Steere et al., 2007). These barriers and the factors that contribute to them will be discussed in this section.

Among contextual barriers, parents have indicated that the stigma caused by disability labels and special education services continues to produce challenges during this period of transition. Parents have described their dissatisfaction with the intense focus on their children's weaknesses during this process (deFur et al., 2001; Salembier & Furney, 1997). In fact, the negative tone of these meetings, feelings of being excluded, and low expectations based on disability labels have been reported as concerns by students as well as their parents (Feinberg, Beyer, & Moses, 2002; Greene & Kochhar-Bryant, 2003; Harry, 2008; Morningstar et al., 1995). This pessimistic view often leads to a sense of disappointment for families about their children's future lives.

A survey by the National Center for Education Statistics (2001) revealed a relationship between parent involvement and household income as well as parents' educational level. This study's findings showed that as parents' educational level and household income increased, the percentage of parents who attended school activities increased. Contextual barriers, such as low family income, single parent homes, marital and child abuse, or drug usage deterred families from being involved in the education planning processes, which were designed to accommodate families that do not deal with these types of barriers (Geenen, Powers, Lopez-Vasquez, & Bersani, 2003). Furthermore, circumstances, such as lack of transportation, lengthy work hours, lack of childcare, conflicting schedules, and exhaustion often hindered the participation of parents at meetings and in training opportunities provided to parents (Lynch & Stein, 1987;

Turnbull & Turnbull, 2001). When parents are concerned with meeting basic, survival needs, school activities, especially those related to planning for the future, are not likely to be the most pressing priority, and thus, parental participation in the transition planning process may be overlooked (Kim, 2006).

Bureaucratic barriers include the idea that the very structure of special education makes it hard for family members to participate in the educational process (Hanley-Maxwell et al., 1998; Schrag & Schrag, 2004). In the transition planning process, parents generally have to work with different service providers from a variety of adult and community agencies (Irvin, Thorin, & Singer, 1993; Steere et al., 2007). Their understanding of the educational system, acquired through personal experience, does not necessarily apply to the adult systems into which their adolescent will soon be transitioning. Also, lack of programs based on entitlement can be shocking to parents who have been used to working within the school system that provides services based on the needs of their son or daughter (Bambara, Wilson, & McKenzie, 2007; Wehmeyer, Morningstar, & Husted, 1999). Furthermore, lack of knowledge regarding transition and community resources can be concerning to many families. Parents have reported wanting more knowledge about the transition process and their legal rights (Garriott et al., 2000; Guy, Goldberg, McDonald, & Flom, 1997; Salembier & Furney, 1997). Several parents have mentioned having difficulty with terminology in IEPs and other reports, and have expressed concerns about their role on the team as a receiver of information rather than as an equal who also provides input to professionals (Harry, Allen, & McLaughlin, 1995; Landmark et al., 2007; Salembier & Furney, 1997). Unfortunately, several parents who

have children with disabilities feel “disenfranchised and alienated from education systems designed to help their children” (Kroth & Edge, 1997, p.14).

One of the most significant barriers to family participation in the transition process includes professional attitudes. For a variety of reasons, family members have not been equal partners in their children’s education. One factor contributing to this inequitable partnership is the inaccurate beliefs held by professionals about families (Turnbull & Turnbull, 1997). Three myths exist that can lead to unbalanced partnerships with families during the transition planning process. These include the idea that families do not have the knowledge or skills to adequately teach or support their children, the idea that parents are too emotional to objectively evaluate their children, and the idea that parents do not accurately understand the way the education system works (Cutler, 1993). “Moreover, when parents or other family members go to the school and attempt to overcome the various barriers to equal partnership, they acquire a reputation and are sometimes labeled as aggressive or unrealistic” (Wehmeyer et al., 1999, p. 8). As a result of such negative attitudes, parents often perceive that they are being blamed for their child’s problems in school, that they do not know anything, or that they have caused their child to feel isolated (deFur et al, 2001; Garriott et al., 2000). Several parents have reported that school professionals’ attitudes have caused them to feel secluded, suspicious, and not included as a member of the planning team (Hanley-Maxwell et al., 1998).

While parents collectively agree that good relationships and communication with school personnel encourage their participation in the transition process, they also indicate that the negative attitudes of professionals is a major hindrance to their involvement

(deFur & Williams, 2002; Salembier & Furney, 1997; Wehmeyer et al., 1999).

Consequently, the relationship that parents have with school personnel serves as a key factor in their perceptions about both their level of participation and the quality of transition services provided (deFur & Williams, 2002; Kim & Morningstar, 2005; McNair & Rusch, 1991). Despite the need for professionals to promote parent involvement, school professionals often lack the training and skills to collaborate with parents successfully, especially with those who are culturally diverse (Knight & Wadsworth, 1999; Morningstar & Clark, 2003).

Cultural Considerations and Transition Planning

Cultural beliefs and values greatly influence how successful transition to adulthood is defined; however, little attention has been given to this matter in the transition literature (Geenen et al., 2001; Kim & Morningstar, 2005; Trainor et al., 2008). Such lack of concentration in this area may signify the application of a “one size fits all” set of transition services being provided to students, without taking into account the effects on families who come from culturally diverse backgrounds (Kim, 2006). Specifically, values regarding adulthood that are associated with mainstream cultural beliefs, such as independence and autonomy of children once they graduate from high school, can create conflicts with families who hold different values about adult life, such as interdependence and family roles and relationships (Harry, 2008; Kalyanpur & Harry, 1999; Luft, 2008; Turnbull & Turnbull, 1996).

As previously indicated, studies show the importance of family member participation in transition planning and follow through (Devlieger & Trach, 1999; Grigal & Neubert, 2004; Kohler, 1998; Morningstar et al., 1995; Zhang & Benz, 2006). Family

involvement in transition planning and programming is viewed as particularly vital to the success of students with disabilities from culturally diverse backgrounds (Geenen et al., 2001; Greene, 1996). The next section will provide an in-depth exploration of the transition planning process for families that are culturally diverse. First, culturally diverse family involvement will be discussed. Second, practices that enhance the involvement of culturally diverse families in the transition planning process will be detailed. Third, cultural conflicts that can arise in transition planning will be identified as well as contrasting views of disability, family relationships, technology, and time will be explained. Fourth and finally, barriers to culturally and linguistically diverse family involvement will be discussed.

Culturally Diverse Family Involvement. Few studies have focused on the involvement of families that are culturally diverse in the transition planning process (Trainor et al., 2008). Kim and Morningstar (2005) reviewed published research between the years of 1984 to 2004 focusing on parental involvement in the transition process for those who have culturally diverse backgrounds. Only 21 articles were identified as fitting their initial criteria, which included the following: (a) publications about culturally and linguistically diverse populations that directly related to family participation in transition planning meetings; (b) studies published in peer reviewed journals; and (c) literature published within the specified years. They then reviewed these selected articles using the criterion of empirically based research offering evidence (quantitative, qualitative, or both) for results. Only 5 of the 21 articles met their final criteria. Three of the studies collected quantitative data, one study used focus groups to collect qualitative data, and one study utilized a mixed methodology.

Lynch and Stein (1987) studied parents' satisfaction with their child's educational program and parental participation in the IEP planning meeting. Findings indicated that 89% of parents identified as Hispanic reported being satisfied with their children's educational services; however, only 55% reported knowing what services were included in their IEP. In fact, 29% responded that they were unsure of the degree of special education services their children were receiving. Furthermore, 50% of all parents indicated feeling like they had limited participation in their children's IEP meetings. When comparing responses across ethnic groups, African American and Hispanic parents reported feeling significantly less involved than Anglo American parents. Both groups of parents reported contributing considerably fewer suggestions during the meetings and had less knowledge regarding services their children received than did the Anglo American participants.

Boone (1992) investigated the degree to which parent training affected IEP meeting involvement of Asian American parents. Satisfaction survey data as well as observational data focusing on the level of parental participation in educational planning meetings were collected. Research findings indicated that even though parents who received training expressed increased knowledge about the transition process than those who had no training, both groups showed minimal participation during the transition meeting. In addition, most of the Asian American parents expressed satisfaction with the meeting.

The study conducted by deFur and her colleagues (2001) utilized focus groups to explore the experiences of African American parents (75%), Anglo American parents (18%), and Asian American parents (7%) during the transition process and their

relationships with their children's service providers. Results of this study indicated that parent-professional relationships were a key factor influencing parental involvement during transition planning. The major findings of this study described barriers to family involvement and the listed attributes of service providers who make a difference. The barriers reported by these parents included professionals' attitudes, discrimination based on race or ethnicity, and an emphasis on their children's weaknesses. The finding that resonated across all families was the importance of service providers who cared about their children, about them, about the demands on their family, and who believed in the abilities of their sons or daughters.

Geenen, Powers, and Lopez-Vasquez (2001) surveyed parents from four different ethnic backgrounds to explore their level of involvement in different activities related to transition planning and the importance they associated with each activity. They also conducted a similar survey with school professionals to determine differences between their perceptions of parental involvement. Results indicated that parents and professionals commonly agreed upon the activities that are necessary for successful transition planning. However, differences existed among parents in regard to the level of importance associated with the different activities. European-American parents placed more value on school-based activities and reported higher levels of participation in transition planning meetings than parents from culturally diverse backgrounds. In contrast, culturally and linguistically diverse parents reported being more highly involved in planning that focused on nonschool-based activities, such as teaching their children about their cultural background and expectations for their adult life, than did European-American parents. Contrasting with these parent reports, professionals saw involvement of culturally diverse

families in nonschool-based transition activities as reasonably lower than European-American parents. Results such as these indicate that professionals have limited understandings of culturally diverse parent involvement in transition planning activities, which consequently may often lead to cultural conflicts.

Geenen, Powers, Lopez-Vasquez, and Bersani (2003) focused on the experiences of parents who are culturally diverse related to their children's transition process. This study used focus groups, face-to-face interviews, and quantitative survey methods to collect information regarding barriers to involvement and transition related experiences of culturally diverse families. Results of this study identified barriers to participation of parents who are culturally and linguistically diverse, such as discrimination, inflexibility, uncaring service providers, contextual barriers, and the lack of emphasis on cultural and family values. Findings revealed differences between culturally diverse parental experiences and parents from majority cultures. The culturally diverse parents in this study reported more negative experiences and barriers for most of the indicators.

From the results of these studies "it is clear that [culturally and linguistically diverse] families perceive their experiences during transition planning in a significantly different light than their European American counterparts" (Kim & Morningstar, 2005, p. 98). More recently, additional studies have emerged that also support these results (Landmark et al., 2007; Povenmire-Kirk, Lindstrom, & Bullis; 2010). Unfortunately, parents who are culturally diverse more often deal with challenges when it comes to their participation in transition planning. These barriers include negative attitudes of school personnel, cultural insensitivity and discrimination, poverty, limited knowledge, and educational system procedures and policies. "It may be that the field does not have a

foundational understanding of the crucial issues facing [culturally and linguistically diverse] families during transition, and perhaps a direction for further research has emerged” (Kim & Morningstar, 2005, p. 98). Based on the aforementioned studies, several practices that can be used to enhance the transition planning process with parents who are culturally diverse have been identified. These practices are discussed in the following sub-section.

Practices that Enhance Transition Planning. Practices that can be used to work more successfully with parents who are culturally diverse have been identified in the literature. These practices can be categorized into three main groups: (a) increasing the cultural competence of service providers; (b) increasing family empowerment; and (c) increasing the use of informal supports (Kim & Morningstar, 2005).

Lynch and Hanson (2004) have stated that everyone has a cultural background that influences our belief systems and behaviors. Many agree on the obvious need for cultural competence training of professionals who provide transition services to students with disabilities (Kim & Morningstar, 2007; Povenmire-Kirk et al., 2010; Trainor et al., 2008). Lynch and Hanson (1993) have defined cultural competence as “the ability to think, feel, and act in ways that acknowledge, respect, and build upon ethnic, cultural, and linguistic diversity” (p. 50). This requires four main actions on the part of the professional. First, service providers must know their own views of the world. This is done by becoming “aware of the cultural values and expectations embedded in their own perspectives of transition regarding work, community integration, role expectations, and social functioning” (Kim & Morningstar, 2005, p. 99). Second, service providers must get to know the families in the community in which they work. This can include

gathering information about family member's roles, communication styles, perspectives on disability, family structure, and successful adulthood, family customs and traditions, and socio-economic factors of the family (deFur & Williams, 2002; Geenen et al., 2001; Kalyanpur & Harry, 1999; Lynch & Hanson, 1998; Salend & Taylor, 1993). Third, service providers must acknowledge and respect cultural differences. This requires openness to learning and willingness to use alternative strategies when faced with conflicts reflecting differences in culture (Kalyanpur & Harry, 1999; Lynch & Hanson, 1998). Last, mutual goals between families and service providers must be developed. This can be accomplished through identifying conflicts, having open communication with families during problem solving, and identifying sources to help resolve disagreements and promote mutual agreement on goals (Povenmire-Kirk et al., 2010; Wolfe, Boone, & Barrera, 1997).

There is a need to empower families by providing knowledge and understanding related to transition issues and encouraging participation of extended family members as well as providing parent support programs (Kim & Morningstar, 2005). In order to increase the involvement of extended family members, service providers can gather information on supports these special family members can provide, identify the roles they can play, and specifically include them in the planning process (Greene & Kochhar-Bryant, 2003). Providing parents with support systems can be helpful throughout their child's time in the public school system; however, during the period of time when their child is transitioning to adulthood, supports are even more vital. Service providers can create opportunities for parents to network through the use of parent-focused trainings, social events, and parent phone-trees. Finally, increasing the use of informal community

resources—such as extended family members, members of their church congregation, and social groups—instead of focusing on seeking help from professional settings, will be beneficial to help service providers avoid conflicts that may arise when working with these diverse families.

Although culturally sensitive strategies are available in the literature that indicate how service providers can better support diverse families, research on parent involvement/satisfaction and large-scale outcomes-based data do not show positive findings for this group of individuals. In actuality, conflicts between families who are culturally and linguistically diverse cannot be avoided. These conflicts will be discussed in the following section.

Transition Planning and Cultural Conflicts

By their very nature, societies use cultural values to determine interactions and perceptions of how specific processes should be organized (Brislin, 1993; Lewis, 1997). Through this process, culture acts as a means for social oppression and control (Gray, 1997). Cultural values and beliefs of the majority population are formalized by the development and passage of legislation and policies (Cordeiro, Reagan, & Martinez, 1994; Nieto, 2000). The IDEA mandates have created four essential elements of transition, which represent a number of formalized sets of values that can clash with the values of families from culturally and linguistically diverse backgrounds (Luft, 2005).

“The first essential element, *consideration of the student’s needs, interests, and preferences*, mandates that transition teams individually assess students’ preferences for their future career and lifestyle” (Luft, 2005, p. 278). Being able to eloquently express oneself is a skill some families value highly (deFur & Williams, 2002). The cultural

values that support such planning emphasize independence and self-sufficiency as a way of achieving personal success (Althen, 1988; Dunn & Griggs, 1995; Green, 1999; Hanson, 1998; Harry, 1992; McPhatter, 1997). However, many other cultures value and prefer belonging to a group over becoming independent or self-sufficient (Chan, 1998; Hanson, 1998; Harry, 1992; Joe & Malach, 1998). Their cultural beliefs emphasize the importance of the needs and interests of the group as a whole over individual preference. They may reject the notion that their children have a right to make choices for themselves in favor of the idea that the family's needs take priority over the needs of the individual.

Several cultures emphasize group identity rather than individualism, and the child's future roles may be defined by his or her place within the family or group structure. The family also may disagree with, or see as destructive and undermining, transition team goals to develop their child's independence, self-reliance, and abilities to make his or her own decisions and choices (Luft, 2005, p. 286).

In these families, interdependence is the primary value, and contributing to the family as a whole is more important than expressing independence or working toward personal gain/achievement (Gil-Kashiwabara, Hogansen, Geenen, Powers, & Powers, 2007; Marin & VanOss Marin, 1991).

“The second essential element of transition planning is to use an *outcome-oriented* [or *results-oriented*] process” (Luft, 2005, p. 278). Positive post-school outcomes are highly defined by one's cultural background (Nieto, 2000). For example, some people view post-school outcomes, such as financial success, material possessions, and higher social status, as positive. Achieving these things, for many people, results in feelings of success and contentment. By extension, educators who subscribe to this philosophy may want these same outcomes for their students. The family, however, might want their child to continue living at home where he/she can be cared for and to

work with a neighbor or family friend in a part-time job (Harry, 1992; Turnbull, Barber, Kerns, & Behr, 1995).

Kraemer and Blacher (2001) found that while post-school expectations for their children varied, many parents envisioned a future in which their child with significant disabilities is living in the family home. Concerns have also been expressed in regards to who would take care of the individual when the parents are gone. This issue is compounded if the extended family still lives in the country of origin. These researchers also found that for those parents who envisioned their child living outside the family home, they envisioned their son or daughter also being gainfully employed. However, only one parent felt like a sheltered workshop was the appropriate place for their child to find employment. Because some cultures do not use economic productivity as an indicator of a person's worth (Harry, 1992), families from different cultures, may not expect or encourage all of their children to be employed, especially any individual with severe disabilities (Ferguson, Ferguson, & Jones, 1988; Kraemer & Blacher, 2001).

“The third essential element of transition planning is *coordinated interagency responsibilities or linkages*” (Luft, 2005, p. 279). Representatives from adult service agencies, who may potentially be providing support to students once they exit the school system, must be invited to participate in the transition planning process. However, some families may prefer to seek supports and resources within their own extended network of family and friends or through more familiar community organizations, such as their church. “Some cultures have great difficulty in seeking help or in disclosing a need for help, and may not feel comfortable with a large group of [unfamiliar] individuals . . . discussing their or their child's needs” (Luft, 2005, p. 279). Since adult service providers

typically meet with parents only once or twice throughout a child's transition program, parents may be resistive to the suggestions and supports offered by these unfamiliar individuals.

“The fourth [and final] essential element of transition is *movement from school to postschool activities*” (Luft, 2005, p. 279). Post-school activities set forth by IDEA include post-secondary education, living independently, being employed, community participation, and appropriate utilization of adult services. Cultural conflicts may arise when these expectations differ from those held by families, for example, viewing unmarried children who live outside the family home as an indication of dysfunction within the family (Gil-Kashiwabara et al., 2007; Turnbull et al., 1995). In terms of post-school activities, some families might prefer that their children with significant disabilities remain living at home where they can be cared for and protected by people who love them. “Beliefs and values associated with education and development of job skills also vary” (deFur & Williams, 2002, p. 111). Some people view education as an honorable pursuit while others may view it as necessary in order to improve their family status (deFur & Williams, 2002). Some families may be reluctant to pursue plans that appear unrealistic to them or post-school goals that have no value in their cultural framework. Transition teams who develop plans that conflict with the family's cultural values, beliefs, and expectations may be surprised later to find that their careful planning has not resulted in success.

The potential for clashing values between the majority culture and a given minority culture does not end with the four essential transition elements discussed above. There are in fact other value sets that can create points of conflict (Lynch & Hanson,

1998). These value sets include contrasting views of disability, contrasting views of family relationships, contrasting views of technology, and contrasting views of time. Although not directly in conflict with transition mandates, these value sets can lead to misunderstandings between families and school personnel, which in turn, breaks down the partnerships that are so desperately needed.

Contrasting Views of Disability. Family views of disability vary along a continuum (Gil-Kashiwabara et al., 2007; Lynch & Hanson, 1998). Some families view disability as pervasive and something that cannot be overcome (Bryan, 1999). Other families may see disability as punishment for their sins (Cabbill & Gold, 2001). Still other families view disability as part of normal existence (Skinner, Bailey, Correa, & Rodriguez, 1999), while others view disability as situational and environmental (Joe & Miller, 1987). Byford and Veenstra (2004) reported that a large percentage of families who had a child with a disability in Papua, New Guinea attributed disability to sorcery or supernatural causes.

The medical model has often been used to diagnose and treat individuals with disabilities in the United States. As a result, a long list of disability categories has been identified; however, many of these disabilities are not recognized by all cultures (Ysseldyke, Algozzine, & Thurlow, 1992). For example, some cultures view mild learning and emotional disabilities as part of a typical range of behaviors; only recognizing disabilities that are more obvious such as physical disabilities (Harry, 1992; Zuniga, 1998). Parents may lack the sense of urgency when it comes to remediation and intervention since they do not understand why their children are struggling in the school environment. For children who have mild disabilities, their families may view the

school's complex transition planning process as unnecessary. "Families may not view transition planning as important because they do not foresee a future that is problematic. They believe that the family or community structures will provide the necessary supports" (Luft, 2005, p. 289). Furthermore, those who believe that a disability reflects negatively upon their family may not be comfortable discussing disability related issues in the amount of detail that schools prefer.

Contrasting Views of Family Relationships. Family networks, which can be made up of large families with extended kinships, may provide support for family members (Billingsley, 1974). These networks can also push family members to make certain choices for their offspring that may differ from those recommended by the dominant culture. For example, an older child in the family might be expected to work in order to send younger brothers and sisters to college, delaying his/her own future plans (deFur & Williams, 2002). Family networks can also be made up of smaller families who do not have these same pressures in decision making but have limited resources and supports (deFur & Williams, 2002; Dickerson, 1995). Also socialization within the extended family network, in some cultures, can be valued more than friendships outside of the family (Blacher, 2001; Blue-Banning, Turnbull, & Pereira, 2002; Lehmann & Roberto, 1996). Culturally diverse families who have students with significant disabilities may also need to deal with the issue of having little support outside the nuclear family because their extended family has not immigrated to the United States (Lehmann & Roberto, 1996).

Contrasting Views of Technology. Although the dominant culture in America is known for pursuing the latest innovations and preparing for the future (Bryan, 1999),

many people from other cultures place great importance on ancestral rituals and traditions (Rogers-Dulan & Blacher, 1995). According to deFur and Williams (2002), “the latest technology or the newest approach to teaching may be regarded with disinterest or suspicion” by such families (p. 111). For example, some parents from different cultures with children who have significant disabilities refuse to use alternative communication devices due to their perception of them as unnatural and stigmatizing. However, they have reported the desire to be able to improve communication with their child and the need for siblings and members of the extended family to receive training and support in using these communication systems (Kemp & Parette, 2000; Lynch & Hanson, 1998).

Contrasting Views of Time. The concept of time is viewed differently by various cultures (deFur & Williams, 2002). Families from some minority cultures do not believe that interactions should be limited by time constraints. This can conflict with service providers who have set a specific timeframe for an IEP meeting or conference. For example, some Native American people have communication styles that are much less direct and that incorporate times of silence. Valuing directness and efficiency through the use of timelines and agendas can very negatively affect trust, communication, and participation in the decision making process, especially when those decisions have the potential to impact the future (Dunn & Griggs, 1995). Other families may perceive punctuality to be an indication of the importance someone places on a meeting, and may believe that their child’s needs are not important when professionals arrive late or leave early (Bryan, 1999). Families who put emphasis on the present may struggle to think about and plan several years into their children’s futures (deFur & Williams, 2002; Marin & VanOss Marin, 1991).

It is important to keep in mind that cultural tendencies are given only as a guide and do not exist at the same level and intensity in every individual who is culturally and linguistically diverse. Making generalizations must be avoided due to the fact that they only breed stereotypical thinking (Milian & Correa, 2001). Regardless of where a student and family falls with regard to issues, such as time, it is imperative to use caution when planning the future lives of these students (deFur & Williams, 2002).

Barriers to Culturally Diverse Family Involvement

Several specific barriers are experienced by families from culturally diverse backgrounds (Bakken & Aloia, 1999; Kemp & Parette, 2000; Kim, 2006; Povenmire-Kirk et al., 2010; Valenzuela & Martin, 2005) that often limit their participation in the education and transition planning processes of their children. These barriers can include cultural insensitivity, primary language differences, unfamiliar educational practices, and conflicting perspectives of parental involvement (Al-Hassan & Gardner, 2002; Geenen et al., 2003; Harry, 1992; Kim, 2006; Sileo, Sileo, & Prater, 1996; Thorp, 1997).

Despite the increasing number of parents and students who are culturally diverse in the United States, the majority of professionals in the school system come from Anglo American, middle-class backgrounds (Boyer & Mainzer, 2003; Geenen et al., 2001; National Center for Education Statistics, 2007; Sileo & Prater, 1998; Thorp, 1997). Parents who come from diverse cultural backgrounds often reported experiencing cultural insensitivity and discrimination from their child's school (deFur et al., 2001; Geenen et al., 2001; Harry, 1992). Not only can this result in families feeling devalued and disrespected, but it can also convey a sense of ignorance on the part of service providers

with regards to students' disabilities and families' cultural backgrounds (Kim, 2006; Kim & Morningstar, 2005).

Limited English proficiency is a common factor affecting family involvement since linguistically diverse parents may feel hesitant when communicating with service providers and may feel intimidated by professionals who are highly educated (Povenmire-Kirk et al., 2010; Salend & Taylor, 1993; Sileo et al., 1996). Furthermore, parents may not understand school documents and reports because of limited English proficiency or an inability to read even in their primary language (Thorp, 1997; Turnbull & Turnbull, 2001). Thus, linguistically diverse parents might not obtain a complete understanding of the educational services that their child is receiving through traditional modes of communication (Al-Hassan & Gardner, 2002).

Families who have recently migrated to the United States, especially those from other countries where laws do not exist for educating children with disabilities, may be unfamiliar with established educational practices and their legal rights (Al-Hassan & Gardner, 2002; Landmark et al., 2007; Lynch & Stein, 1987). Thus, parents may be unaware of existing special education services and issues that can affect their children's education (Landmark et al., 2007; Lynch & Stein, 1987; Salend & Taylor, 1993; Sileo et al., 1996). This can contribute to limited family involvement in the decision-making process. For example, one study revealed that Puerto Rican parents felt they had little input in transition planning for their children, although they felt like they had important information to contribute (Harry, 1992).

Families from diverse cultural backgrounds may feel especially disempowered by the educational system in the United States (Turnbull & Turnbull, 2001). According to

some cultural beliefs, educational planning and decision making is the responsibility of the educational professionals (Greene, 1996; Lynch & Hanson, 2004; Lynch & Stein, 1987). Some families may perceive their role as deferring to those individuals who are in a position of authority. This can lead parents to refrain from offering their input and opinions when they differ from those of school personnel (Boone, 1992; Sileo & Prater, 1998). As a result, this behavior may be misinterpreted by professionals as disengagement or lack of interest on the part of the parents (Harry, 1992; Steere et al., 2007). Furthermore, some families who have recently immigrated to the United States might not be accustomed to participating in the educational process of their children and can perceive their involvement as inappropriate (Al-Hassan & Gardner, 2002; Thorp, 1997).

In summary, the aforementioned barriers can result in limited parent involvement and may lead parents to feel frustrated and isolated throughout their child's transitional period, which can in turn result in parents' withdrawing from this process (Garriott et al., 2000; Guy et al., 1997; Harry et al., 1995; Kim, 2006). Systematic approaches are needed to improve collaboration between families and service providers if transition planning is to be successful for these students.

Implications and Other Considerations

The often undetected values and beliefs associated with culture can be difficult to study and analyze (Luft, 2005). Culture is made up of the "ideals, values, and assumptions about life that are widely shared among people and that guide specific behaviors" (Brislin, 1993, p. 4). It also consists of "the complex, changing nexus of values, attitudes, beliefs, practices, traditions, and social institutions . . . of a community"

that includes religion, language, foods, history, and dress (Cordiero, Reagan, & Martinez, 1994, p. 20). These values, beliefs, and attitudes remain mostly internalized until called upon to guide a person's actions. When specific values and beliefs remain unchallenged, there are no outward actions that lead a person to focus on them (Brislin, 1993). For example, personal hygiene is typically not a focus of someone's day-to-day interactions until challenged by a person who does not meet expected levels of cleanliness. When these differences occur, the typical reaction is to validate one's expectations and express the importance of these values. In this example, someone might express the importance of his or her belief by explaining the significance of daily and meticulous hygiene practices. Without the knowledge of cultural differences, conflicts may increase with every encounter. These cultural violations can often result in negative emotional reactions. Fortunately, an increased knowledge of cultural differences can lead to a decrease in discomfort felt when confronted with cultural conflicts (Brislin, 1993). This is an essential requirement when trying to create positive relationships with culturally diverse families, and ultimately, in establishing effective partnerships among all members of a student's IEP team (Luft, 2005).

Despite the overwhelming importance of these issues, an investigation of the literature on multicultural special education from 1975 to 2002 found that less than 5% of studies published in five major special education journals addressed issues of cultural and linguistic diversity (McCray & Garcia, 2002). A large proportion of these publications focused on concerns of identification and assessment of this group of students. However, these studies do not necessarily provide information about culturally diverse students who do have disabilities. Their analysis also revealed that quantitative studies

outnumbered qualitative studies by an approximate 3:1 ratio. The findings from Kim and Morningstar (2005) support the lack of research in this area. Pugach (2001) suggested that cultural differences have not yet been recognized as a valid area of content in the knowledge base of special education. More research is needed in order to provide contextual information that will add a significant contribution to the literature in this area and will aid future research in the pursuit to identify best practices in transition services for students with disabilities who are culturally diverse (deFur & Williams, 2002; Trainor et al., 2008; Wehmeyer et al., 1999).

Research in an Evidence-Based World

Several federal initiatives facilitating the transition of students with disabilities from adolescence to adulthood have been established between 1983 and 2003. These initiatives were intended to support program development, personnel preparation, research efforts, models for developing transition programs, and postsecondary education demonstrations. The result of these initiatives in the areas of research, model programs, and systems change activities is a large body of literature that appears in professional journals (Alwell & Cobb, 2006a), reports (Wagner et al., 2005), manuals (Leake & Black, 2005), and textbooks (Sitlington & Clark, 2006).

Political beliefs of our current time value and promote a particular perspective that is derived from group design studies, high academic standards, and evidence-based research. In addition, the federal government is currently supporting the syntheses of previously collected data in order to identify evidence-based practices. For example, it would support conducting a meta-analysis of experimental and quasi-experimental studies on literacy interventions used with students who have significant disabilities in

order to identify those practices that statistically show a significant effect on the literacy skills of this group of children (Browder, Wakeman, Spooner, Ahlgrim-Dezell, & Algozzine, 2006). There is little doubt that this type of research will be useful to practitioners and policy makers in identifying interventions that contribute to optimal outcomes for specific groups of students.

Experimental research of this type, which is certainly important, is driven by positivistic assumptions, which aim to identify an independent, measurable, and objective reality (Harding, 1991; Lather, 1991; Lincoln & Guba, 2000). On the other hand, qualitative research methodologies, such as those used in this study, are grounded in a different view of reality. This view of reality recognizes the importance of the perceptions and understandings of the people that are served by the research discussed above. Within this line of research, the focus shifts from measuring and analyzing interventions and outcomes to exploring ways in which individuals and societies, in general, construct meaning. This type of research offers an important counterbalance to quantitative research.

Skrlic (1995) has asserted that much of the failed progress within education, including special education, has come about because of a focus on interventions without a deeper consideration of the paradigm that drives the thinking behind the interventions. Put differently, the field continues to cover the same ground, making little substantial progress, because its efforts are directed at creating interventions deeply embedded in a web of assumptions that have, themselves, never been adequately questioned.

Skrlic has argued that a solution lies in a “critical discourse on the level of grounding theories or paradigms that ultimately is concerned with the nature and effects

of special education models and practices” (p. 67). According to Skrtic (1995), theoretical grounding is required for systemic change to take place in special education.

Norman Kunc, in his work in the area of disability studies, has presented a similar point. He has argued that the relentless search for new interventions is misguided:

You don’t gain the ability to deal with the complexity of people just by acquiring an abundance of strategies. You gain the ability to deal with the complexity of people from depth of thought. Many people avoid seeking this depth of thought because they are too busy acquiring this endless library of disjointed strategies (in Giangreco, 1996, p. 7).

The present study was designed to contribute to the kind of discourse that Skrtic recommends, and that Kunc supports. By systemically examining parent experiences with and perspectives on the transition services that are provided to their children, a deeper awareness of impact, benefit, and effects of those services can emerge that may begin to challenge the assumptions behind present intervention practices.

Further Rationale for a Qualitative Approach

“Qualitative researchers are interested in understanding the meaning people have constructed, that is, how they make sense of their world and the experiences they have in the world” (Merriam, 1998, p. 6). Such researchers seek answers to questions through the meanings people connect to particular situations and experiences. The use of qualitative methodologies allows the researchers to understand these meanings within the framework of the lives of the participants.

Qualitative research methods encourage those being studied to speak for themselves and to tell their own stories (Crotty, 1998). It can lead to a more holistic understanding of the phenomenon of interest from the participants’ perspectives and will provide the researcher with needed background knowledge to more accurately draw

conclusions from their data and support their findings (Merriam, 1998). Qualitative research methods have been recognized as especially appropriate in the pursuit of understanding the experiences of diverse groups of people (Lincoln & Guba, 1985).

Denzin and Lincoln (2005) suggested that an intimate relationship forms between researcher and participant. This relationship is also influenced by various elements that shape the process of inquiry, such as topic, amount of time and resources, age, gender, and the ethnicity of researcher and participant. Due to these situational components, it is ideal that “the design of a qualitative study is emergent and flexible, responsive to changing conditions of the study in progress” (Merriam, 1998, p. 8).

Creswell (1998) has provided four reasons for conducting a qualitative study. First, the study should be designed according to the data required to answer the researcher’s questions. Creswell notes that qualitative research is designed to answer what and how questions, such as those guiding my study.

Second, when conducting research on a topic requiring in-depth exploration and descriptive detail, qualitative methodologies are especially appropriate. As with the first of Creswell’s reasons for choosing qualitative methodologies, this second reason also matches the needs of this study. A deep and richly described analysis of the pattern of experiences of the study’s participants will best answer the research questions.

Third, Creswell recommends that qualitative research methodologies are especially useful when examining the experiences and perceptions of people within their natural settings. The present study seeks to understand transition services as they are understood by parents who are part of these services.

Finally, a qualitative approach should be used when a researcher sees his/her “role as an active learner who can tell the story from the participants’ view rather than as an ‘expert’ who passes judgment on participants” (Creswell, 1998, p. 18). This was precisely the aim of this study.

Tools of a Qualitative Approach

Qualitative research makes use of a variety of resources to gain insight into the stories associated with moments in individuals’ lives. “The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell, 1998, p. 15). Qualitative research is judged primarily on its ability to accurately communicate the reality of a situation as viewed by those involved (Merriam, 1998). In order to ensure the quality of this study, the four basic elements of well-designed research that are offered by Crotty (1998) were utilized: epistemology, theoretical perspective, methodology, and methods. These are described in detail in the next chapter.

To ensure rigor, this study relied on multiple forms of data and ample time was spent gathering data in the field. This study also incorporated characteristics, such as an evolving research design, inclusion of multiple realities, the researcher as the primary data collection instrument, and participant views as the focus.

Crotty (1998) has suggested that regardless of how strictly the researcher adheres to a rigorous research method, results remain partially subjective and to an extent uncertain. Qualitative research “assumes that there are multiple realities; that the world is . . . a function of personal interaction and perception” (Merriam, 1998, p. 17). Therefore,

despite efforts to accurately interpret the words of each participant, it was impossible to refrain from contributing my own perceptions and biases to the data.

Role of the Researcher in a Qualitative Approach

As the primary instrument used in data collection and analysis, the researcher must develop and refine specific personal characteristics and skills that will permit him or her to be an effective researcher. The researcher must, for example, be tolerant of the uncertainty that can exist when conducting qualitative research. This “lack of structure . . . allows the researcher to adapt to unforeseen events and change direction in pursuit of meaning” (Merriam, 1998, p. 20-21).

The qualitative researcher must be intuitive on several different levels of the research process. Sensitivity to all variables within the context of the study, including the information being gathered, the participants and their environment, verbal and nonverbal behaviors, and any personal biases that might influence the study, must be present. To accomplish this, the researcher must be a good communicator who “empathizes with respondents, establishes rapport, asks good questions, and listens intently” (Merriam, 1998, p. 23).

As in any form of inquiry, a research instrument must be assessed as to its reliability to provide an accurate measure of the data. Thus, the lens through which I view the world, and therefore the lens through which I interpreted the data, must be evaluated. In the Chapter III section entitled, *Through the Lens of the Researcher*, I describe the experiences that have shaped my perspective on transition services for students with significant disabilities.

Summary

For over two decades one of the most vital areas of service in special education has been the transition of students with disabilities from the school system to adulthood (Halpern, 1985; Landmark et al., 2010; Sitlington & Clark, 2006; Will, 1984). Despite improvements made since the inception of the transition movement, students with disabilities continue to experience poorer post-school outcomes than students without disabilities (Blackorby & Wagner, 1996; Blackorby et al., 2007; U.S. Department of Education, 2001; Wagner et al., 2005; 2006). Likewise, students from diverse cultural background also experience even more challenges during their transition to the adult world (Lehr, Johnson, Bremer, Cosio, & Thompson, 2004; National Council on Disability, 1999; Trainor et al., 2008; Wagner et al., 2005).

Most of the early work in this area focused on identifying necessary factors that might lead to improvements in employment and personal outcomes for these students. Best practices that are most frequently mentioned include transition planning that is individualized, on the job work experience and employment training, collaboration among agencies, and family participation in the transition planning process (Benz et al., 1997, 2000; Kohler, 1998; Kohler et al., 1994; Morningstar et al., 1999). The most current research and literature adds focus on new practices, such as transition assessment, self-determination and student involvement, and person-centered planning.

Of all of these, family participation is increasingly viewed as one of the most essential factors leading to successful transition planning and post-school outcomes for students with disabilities (Kohler, 1998; McNair & Rusch, 1991; Morningstar et al., 1995). Specifically, parents can help service providers in the process of developing post-

school goals and plans by providing the necessary information on the strengths, needs, interests, and wishes of their sons/daughters with disabilities (Brotherson et al., 1993; Hanley-Maxwell et al., 1998). Furthermore, parents often continue to take on supportive roles long after their children leave school, especially for students with significant disabilities (Morningstar et al., 1995; Hanley-Maxwell, et al., 1998; Steere et al., 2007). For most of these students, family members serve as one of the only constant sources of support over their lifetime (Brotherson et al., 1993; Hanley-Maxwell et al., 1998). Unfortunately, despite the identified importance of family participation in the transition planning processes, research continues to report that family members consistently describe their role as passive participants (deFur et al., 2001; Garriott et al., 2000; Geenen et al., 2001; Salembier & Furney, 1997).

Several barriers have been identified as causing the limited participation of families, including culturally diverse families, in the education of students with disabilities (deFur & Williams, 2002; Garriott et al., 2000; Geenen et al., 2003; Kim & Morningstar, 2005; Salembier & Furney, 1997). Among the identified barriers, families agreed that the negative attitudes of service providers was a major challenges preventing their participation, while they also had a consensus that good relationships and effective communication with professionals promoted their participation in the transition process (deFur & Williams, 2002; Salembier & Furney, 1997; Wehmeyer et al., 1999).

Despite the need for service providers to promote family member participation, they lack the knowledge and skills required to work effectively with them, especially with culturally diverse families (Knight & Wadsworth, 1999). Training in and learning about cultural differences has shown to decrease negative emotional responses and

discomfort when faced with a culturally conflicting situation (Brislin, 1993). This is important for establishing relationships with culturally diverse families that will lead to more collaborative and effective interactions among all team members.

An examination of existing literature on multicultural special education from 1975 to 2002 found that less than 5% of studies published in five major special education journals addressed issues of cultural and linguistic diversity (McCray & Garcia, 2002). Furthermore, Kim and Morningstar (2005) identified only 5 studies in their review of published research between the years of 1984 to 2004 regarding family participation in transition for families that are culturally diverse. The purpose of the present study is to provide contextual information that will add to the literature in the area of transition services and will aid future research in the pursuit to identify best practices in this area for students with disabilities who are culturally and linguistically diverse (deFur & Williams, 2002; Wehmeyer et al., 1999). In the next chapter, the specific epistemology, theoretical perspective, methodology, and methods used to guide collection and analysis of the data are described.

CHAPTER III

METHODOLOGY

The primary purpose of this study was to gain a better understanding of the perspectives and experiences of parents who are culturally and linguistically diverse during the transition process of their children with significant disabilities from adolescence to adulthood. To ensure the reader has a full understanding of the present study, this chapter begins with a discussion of the research method and paradigm, followed by a detailed description of the multiple case study approach, including participants, data collection, data analysis procedures, and methods used to enhance trustworthiness of the findings.

Through the Lens of the Researcher

My interest in transition of students with significant disabilities from the school system to adult life began several years ago when I first began supporting high school students in a rural town in southern Colorado. At that time, I approached the transition process as one in which students with disabilities were provided with supports and opportunities to help achieve a high quality of life after exiting the school system. This type of programming included providing students with opportunities to be engaged in general education environments leading to the development of appropriate social skills, supported employment, field trips to local community colleges, instruction in daily living skills, household and money management skills, and community functioning skills. It

also included connecting students and their families with various community agencies that could provide resources and supports after high school graduation. The primary focus of my efforts was to help students achieve independence to the highest extent possible.

Three main post-school outcomes directed my efforts for these students. First, some type of employment or employment training that would be maintained after graduation was put into place. Second, independent living situations, such as group homes or independent living environments, were identified and plans of action were developed to ensure the likelihood that students would eventually live in these settings. Third and finally, social and recreational activities within the students' communities were investigated and identified as possible post-school options for these students. For example, obtaining a membership to the local health club or becoming a member of a community organization, might be options that I explored.

It was my belief that if these students were able to obtain some level of these three post-school outcomes that they would have a higher quality of life and thus, my efforts would be successful. I had several students graduate from high school while receiving services from my program, and I often wondered if I had provided the best services to them. Had I provided services that would actually help them become successful adults? What level of quality of life would they have after they were out of the school system? Would services I provided in school lead to higher quality of life for these students? Thoughts like these placed an enormous sense of obligation and responsibility on me to provide the best services to students on my caseload as possible.

As I entered doctoral study, I continued to research issues surrounding this topical area. Overwhelmingly, this research indicated that students with more significant disabilities had poor post-school outcomes. However, it has only been recently that I have become aware that post-school outcomes such as living independently, obtaining employment, accessing post-secondary education, and seeking relationships outside the family were sometimes in conflict with cultural values of some families. Armed with this new information, I now realize that I may have unintentionally provided inappropriate services to the culturally and linguistically diverse families that I worked with in my predominantly Hispanic community.

The discrepancy between my past practices and current research on transition outcomes has influenced my desire to conduct research in this area. It is my hope to contribute valuable information that will help to develop practices for transition services that are more reflective of cultural differences. My personal experiences, beliefs, and values provide an explanation for the way I see the world and establish my role in the research process, and they have influenced my choice of research model and paradigm.

Research Model and Paradigm

Crotty (1998) describes four basic elements of social sciences research, and how each of these guides the research process. These elements include epistemology, theoretical perspective, methodology, and methods. In this section I have summarized each of these elements and how they have been applied to this study.

Epistemology

Epistemology has been defined by Schwandt (2001), “as the study of the nature of knowledge and justification” (p. 71). In other words, epistemology is “how we know

what we know” (Crotty, 1998, p. 8). Crotty (1998) has recognized three fundamental epistemologies: objectivism, constructionism, and subjectivism. The epistemology most representative of this study is subjectivism.

According to Crotty (1998), in subjectivism meaning is not constructed from interactions between a participant and some object or situation but rather is placed on the object or situation by the participant. Therefore, only the individual makes contributions to the creation of meaning. Subjectivism views judgments or interpretations as descriptions of feelings, attitudes, and beliefs held by an individual (Schwandt, 2001). The meaning we assign to objects or situations stem from our life experiences, from our religious and cultural beliefs and values, or from our collective unconscious (Crotty, 1998).

In this study, participants’ meanings and interpretations of their experiences during the transition process of their children with significant disabilities was solicited. Participants had the freedom to relate their understandings and experiences through their stories and words. Each participant had the opportunity to verify his or her interview transcripts as to their accuracy; however, the responsibility of compiling, interpreting, and presenting the findings was ultimately that of the researcher. The following discussion further clarifies my theoretical approach to this study.

Theoretical Perspective

School systems are structured so that some students’ abilities are enhanced and stimulated at the expense of the abilities of others (Merriam, 1998). Students with disabilities are one group of students who have been oppressed in our school systems, and those who are also culturally and linguistically diverse are even more oppressed.

Similar to the segregation of African American students throughout history, these students are not receiving the same opportunities as other students in school. When looking at post-school outcomes for these students, these differences become glaringly apparent.

The theoretical perspective that best represents my views of the world and therefore, describes my beliefs that contribute to the methodological design of this study is critical theory. Developed in the 1920s through the Frankfurt School, critical theory can be described as a combination of “practical philosophy and explanatory social science, sharing and radically reforming the intentions of both” (Schwandt, 2001, p. 45). Some of its basic principles were formulated earlier by Friedrich Hegel and Karl Marx. The basic assumption of critical theory is that people are in a constant power struggle against social domination (Crotty, 1998). It is also assumed that power operates to impose constraints and to sustain control of those people who are not in power (Creswell, 1998). The central purpose of critical theory is to facilitate change in economic, political, and social systems that minimize the voice and power of the oppressed.

Critical theorists believe that certain groups in any society are privileged over others, constituting an oppression that is most forceful when people accept their social status as natural, necessary or inevitable. For example, life experiences determine the complexity of cultural development; however, the dominant culture determines to a considerable degree the type of experiences an individual encounters (Bryan, 1999). According to critical theory, knowledge is power, and power is related to economic and social class. The dominant culture determines the values to be placed upon certain cultural traits. This, of course, leads to the devaluing of the cultural traits of any group

not included in the dominant culture, including persons with disabilities. Critical theory seeks to identify, challenge, and change this type of status quo (Crotty, 1998).

My study was designed to encourage individuals who have traditionally been oppressed in our school systems and in the transition planning process to examine the conditions of their involvement (Thomas, 1993). The end goal of my study was to understand and, ultimately, transform the underlying orders of the social and systemic structures that constitute this process of transitioning these students and their families into the next phase of their lives (Morrow & Brown, 1994). I accomplished this through investigating a small number of comparable cases of specific individuals (Creswell, 1998). The next section will discuss the research methodology and methods that were utilized in the process of data collection and analysis of this study.

Methodology

Methodology “is the research design that shapes our choice and use of particular methods and links them to the desired outcomes” (Crotty, 1998, p. 7). The methodology primarily utilized in this study was grounded theory. Strauss and Corbin (1998) have defined grounded theory as a qualitative methodology developed to systematically collect and analyze data, and to construct theoretical models. Grounded theory, first presented in 1967 by Glaser and Strauss, assumes an inductive stance and strives to draw meaning from the data. For example, Morrow and Smith (1995) studied women who had been sexually abused as children with the purpose of understanding their lived experiences and generating a theoretical model for the ways in which they survived and coped with their abuse. The data consisted of over 2,000 pages of transcription, field notes, and documents

shared by participants. Over 160 individual strategies were coded and analyzed into the components of a theoretical model.

In grounded theory methodology, predetermined codes and themes typically associated with qualitative research are not utilized. In the above study by Morrow and Smith (1995), the methods used to understand participants' experiences involved developing codes, categories, and themes inductively rather than using pre-established classifications. These classifications were continually sorted, compared, and contrasted until the analysis could no longer produce any new codes or categories.

During analysis the researcher may need to move into the realm of speculation when identifying relationships between categories in order to form a theory grounded in the data (Merriam, 1998). The theory emerging from this process addresses, and is useful for explaining particular situations such as the survival strategies applied by women abused as children when they experience helplessness or lack of control (Morrow & Smith, 1995). As seen in this example, grounded theory is used to understand a specific situation instead of a global situation addressing wider concerns (Merriam, 1998).

Grounded theory is being used more and more in educational research (Charmaz, 2005), ranging from the context of the school system to the individual students. Many times the areas being investigated through grounded theory are primarily those lacking in a long, established research base. The development of a grounded theory can lead to theory building in the field at large. Strauss and Corbin (1998) suggest that findings in one research setting can be valuable when applied to similar phenomenon in another research setting.

The theory that emerged from this investigation provides insights into the perspectives of parents who are culturally diverse and whose children with significant disabilities are going through the transition process. The use of grounded theory permitted the researcher to collect the stories of these parents that illustrate their feelings toward and experiences with the transition process. It also permitted exploring any possible concerns or barriers that parents from diverse cultural backgrounds might face during this time in their children's lives. Furthermore, the use of grounded theory helped to gain a deeper understanding of the expectations of parents and their descriptions of their children's service needs and how these compare to the documented expectations of school personnel and existing services. Multiple visits over time combined with the intimacy of intensive interviewing associated with grounded theory methodology provided a deeper view of the lives of these participants rather than a one-shot structured or informational interview (Charmaz, 2005). At its best, grounded theory also laid a groundwork that goes beyond the current study, thus providing a guide for further research (Strauss & Corbin, 1998).

Interviews are the primary data source typically used in grounded theory (Creswell, 1998). Interviews are especially useful for gathering information when behaviors are difficult to observe, when feelings are being assessed, or when interpretations of situations are being analyzed (Merriam, 1998; Stake, 2005). The reason for conducting in-depth interviews is to understand the life experiences of other people and the meaning they associate with those experiences (Seidman, 2006). Seidman (2006) suggests, "When people tell their stories they are involved in a meaning-making process consisting of selecting constitutive details of experience, reflecting on them, giving them

order, and thereby making sense of them” (p. 7). The researcher can only understand and make meaning of people’s stories when they are put into context of the lived experiences of participants and the experiences of those around them (Patton, 1989).

Methods

According to Crotty (1998), research methods provide the detailed procedures used to gather and analyze data. The research methods must be determined by one’s chosen methodology. The method selected for the research described here was the case study. Several types of case study methods have been described in the literature, which differ by their end-products. Some case studies seek to investigate the relationship between a phenomenon and its natural context (Yin, 1994); others seek to define the boundaries of a particular case within itself (Stake, 1995); and still others produce a “holistic description and analysis of a single instance, phenomenon, or social unit” (Merriam, 1998, p. 21). A definition provided by Becker (1968) best defines the purpose of this study. Case study was used here “to arrive at a comprehensive understanding of the groups under study” and “to develop general theoretical statements about regularities in social structure and process” (Becker, 1968, p. 233).

Stake (1995) identified three other ways that case studies can be characterized: intrinsic, instrumental, and collective. Intrinsic case study seeks to understand a certain case in-depth. An instrumental case study is used to provide insight into a particular issue. Collective case study involves several instrumental cases simultaneously. The present study was a collective case study in which I simultaneously studied five different cases.

Creswell (1998) suggests that the more cases studied, the greater the lack of depth in any single case. He goes on to recommend that no more than four cases be studied since the motivation for more is intent to generalize findings, which is not the aim of qualitative researchers (Glesne & Peshkin, 1992).

Case study research may incorporate a number of different techniques such as observations, interviews, and artifact collection (Merriam, 1998). Although this study utilized all three methods, as noted previously, in-depth interviewing is the primary method when grounded theory is one's methodology. Story telling through structured interviews is an especially effective means for uncovering individual truths and for constructing a theory of how participants understand a particular situation (Seidman, 2006). These interviews were conducted over multiple points in time to permit theory to emerge (Charmaz, 2005).

Procedures

This section describes how participants were selected, the settings in which the study were conducted, the protocol for carrying out the research study activities, and the procedures for gathering data. This section will begin with a discussion of the participants and how they were selected.

Participants

The five families that were used in this study were selected through a purposeful sampling procedure to ensure that they were qualified to provide the necessary perspectives (Creswell, 1998). Several different types of purposeful sampling are available (Merriam, 1998). For the purpose of this study, possible participants were

primarily chosen through a successive sampling process referred to as theoretical sampling.

According to Glaser and Strauss (1967),

. . . theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (p. 45).

This process began with the selection of an initial family that was chosen for its relevance to the study. The data gathered from this family led to the selection of the next family. As data were collected and hypothetical constructs began to emerge the researcher used this selection process to help guide the construction of the theoretical model (Merriam, 1998).

To some extent, this process relied on convenience sampling. Convenience sampling yields a sample based on the researcher's resources, such as time, money, location, availability of sites or respondents. However, every effort was made to employ strategies from theoretical sampling so that an adequate theoretical model emerged from this research.

Three primary selection criteria were used for the identification of participants for this study. First, participants were parents of students with significant disabilities. Second, they were from a culturally and/or linguistically diverse background as defined in Chapter I. Third and finally, their daughters and sons were between the ages of 16 and 21 years and were receiving transition services from a school district or educational entity at the time of this study. Four different cultural backgrounds were represented by the selected participants.

Setting

Some participants chose to be interviewed in their home for all of the interviews and others wanted to be interviewed at a more public place. However, interviews conducted in the home added to the richness of the data because this represents the most natural environment of the family life. Hence, it was my first choice of settings for these interviews.

Data Collection Procedures

Data collection and data analysis are not clearly distinguished from each other in a qualitative study using grounded theory methodology, due to the fact that these two procedures take place at the same time. This section, which describes how this was accomplished, includes the following sub-sections: contact visits, interviews, fieldnotes, document reviews, and demographic information.

Permission to conduct this study was obtained from the Institutional Review Board at the University of Northern Colorado (see Appendix A). After the study was approved by the institutional review board, a pool of potential participants was developed using contacts from previous studies, contacts known by parent advocates, contacts involved in parent support groups such as PEAK Parent Organization and The ARC of Colorado, and contacts suggested by other potential participants.

Prior to conducting interviews, participants were assured of the confidentiality of their statements and were informed of their right to withdraw from the study at any time. Participants were required to sign a Human Subjects Consent Form prior to the interviews (see Appendix B).

Contact Visits. Once an individual expressed interest in participating in the study, a contact visit was arranged (see Appendix C). Consistent with the recommendations of Seidman (2006), these contact visits were preliminary to the actual interview process. These initial contact visits were designed to aid in selecting participants and to help build a foundation for the interview relationship (Seidman, 2006). If potential participants did not want to meet face-to-face for this initial contact, it was completed over the phone or by email. During contact visits groundwork was laid for the mutual respect needed during the data collection phase of this study. The initial contact visits also provided an opportunity to explore the homes or work environments of potential participants before conducting the actual interview (Seidman, 2006).

During this contact, potential participants were also informed of the in-depth interview process and the need for the researcher to review relevant documentation, including a copy of their child's IEP or Individual Transition Plan (ITP). Finally, this initial contact served as a forum for going over information about audio-taping, confidentiality, and the informed consent was signed at this time (Corbin & Morse, 2003).

A database of potential participants' personal information was developed. This information included the participants' address, telephone numbers, email address, and times when they were available to talk and times to avoid contacting them. This information was collected during the initial contact visit. Based on these initial contacts, those potential participants who seemed most suitable to the topic of this study were selected, and the first of these families was invited to participate. Follow-up letters or emails were sent to all remaining potential participants, thanking them and indicating

whether or not they had been selected to participate in this study. So that replacement participants could be identified, the database was maintained as the study proceeded.

Interviews. Qualitative data were collected through various means; however, the primary mode of data collection was in-depth, semi-structured interviews using a person-to-person approach (Schwandt, 2001). Through this process of interviewing, I intended to uncover the stories participants associated with their experiences and perceptions of the transition process of their children with significant disabilities.

For the five selected participant families, there was a series of three separate interviews. Each interview lasted approximately 45 to 120 minutes in length. In order to allow the participant time to mull over the previous interview but not enough time to lose what they had already talked about, interviews were spaced three days to one week apart.

This same process continued across all five participants. After each interview, I listened to and transcribed the raw data from the audio tapes verbatim, and then provided a copy of the transcript to that participant upon my next visit (Merriam, 1998). I stored all data including my field journal, memos, transcriptions, and other observational notes on a computer, each case study in its own file.

Since data collection and analysis occurred together in a sequential fashion (Charmaz, 2000; Lincoln & Guba, 1985), item construction was an iterative process guided by the evolving theoretical structure. Although it was anticipated that three interviews would be sufficient to construct an adequate theory, some additional follow-up contacts were necessary to ensure a fully developed theory (Merriam, 1998; Strauss & Corbin, 1998). These follow-up contacts occurred over email or phone. Upon completion of the study, participants were compensated \$90 for their time.

Dolbeare and Schuman were the first to develop a series of three interviews that would allow a researcher to put the participant's stories into context (Schuman, 1982). Guidelines for this three-interview process set forth by Seidman (2006), was followed in this study. These guidelines are described below.

The purpose of the first interview was to put the participants' experience into context. Seidman (2006) suggests asking the participants to generally describe their experiences associated with the topic up to the present time. The following questions provided the structure for the first of the three interviews:

1. Think about when you were growing up, what was your life like? How many adult workers were there in your household? What type of work did they do? Do you recall your parents juggling their schedules? Did they ever bring work home? Did their work seem to interfere with your being able to spend time with them? Did you experience or your parents experience any stress because of the work schedules of your family? Besides yourself and siblings, did your parents have responsibilities for other family members? If so, who?
2. How is your life now? How is it the same as when you were growing up? How is it different? Do you have responsibilities for other family members, now? If so, who are they and what are your responsibilities?
3. Did your family need any special services when you were growing up, like child care or elder care services? Did your family need to use social or family services of any kind? Did you feel like other extended family members or friends were available to provide you with emotional or financial support when you were growing up?

4. Does your family need any special services now? Does your family need to use social or family services of any kind now? Do you feel like other extended family members or friends are available to provide you with emotional and/or financial support now?
5. Describe a time of difficulty for your family and how you handled this period in your life. When you need support, do you tend to get it from community agencies or do you get it from extended family members and/or family friends? Describe an example of when you might ask for help.
6. How do you make important decisions in your family? Who makes the final decision? Do children in your family participate in making important decisions? If so, how are they involved?
7. Do you encourage independence in your family? Is this expectation different for your son/daughter with a disability? If so, explain why it is different? Does your family value working together rather than working independently? Describe a time when your family has worked together or worked independently towards a goal.
8. Tell me about the time when you first learned about your son/daughter's disability? How was this for you and your family? How do you and your other family members view your son/daughter's disability? How does this view affect the way that you or other family members treat your son/daughter?
9. Tell me about your son/daughter with a disability. (How does your son/daughter fit into your family? Youngest child, oldest child? How many siblings does your

- son/daughter have? What would you say are the defining personal, social, and academic characteristics of your son/daughter? What are his/her strengths/needs?)
10. What is your son/daughter's communication and personal interaction style? Does he/she have well-developed interpersonal communication skills? Does he/she rely more on nonverbal communication than the spoken word?
 11. What does the phrase "changing from being a school child to being a young adult" mean to you? At what age is a child considered an adult in your family? Is this the same for every child in your family? If not, why?
 12. Think about when you were younger. What was this change like for you? Did you stay at home or did you leave at some point? If you did leave home, what was that like?
 13. Think about when other children in your family, your own children, nieces, and nephews, or the children of friends who do not have a disability, were leaving school and becoming young adults. What is your understanding of what is supposed to happen during the time a child leaves the school system and begins his/her adult life? What typically happens to young adults in your family when they leave school and become adults? What was that change like for the family? How does their change compare to the change for your son/daughter with a disability?
 14. What does the phrase "changing from being a school child to being a young adult" mean to you when you think of your son/daughter with a disability?
 15. Do you know what the phrase "transition services" means with regards to your son/daughter's educational programming being provided by the school? If so,

what is your understanding of transition services? How did you find out about these services?

The purpose of the second interview was to allow participants to reconstruct in more detail their present experiences within the context of the transition process.

Although questions for this interview were influenced by the data collected in the first interview, questions such as the following provided a framework for the second set of interviews:

1. Your son/daughter with a disability is now in the process of changing from being a school child to being a young adult. What has this change (from school to adulthood) been like for your family? What is this change like for your son/daughter (prompts: socializing, dating, living outside the home, working)?
2. Is your son/daughter in or preparing to enter any kinds of special programs? If yes, what kinds of programs is he/she in? What do you know about your child's rights in terms of leaving the school system and entering other programs? What services do you think are provided as part of this change? What services should be provided? How do you find out about these services?
3. Does your son/daughter have a plan (IEP? Other?) for his/her life once he/she finishes school? What are his/her goals when he/she finishes school? What are the most important aspects of this change from school child to young adult for your son or daughter? What are the hardest parts? The best parts?
4. Tell me about your son/daughter's Individualized Education Plan. (Have you ever been invited to attend your son/daughter's IEP meeting? Did you attend? Did you ask anyone else to go to the meeting with you for support? Did you know that

during the meeting you would be discussing goals, services, and supports that your son/daughter might need after they get out of school?)

5. What current services are being provided to your son/daughter to help him/her once he/she leaves the school system? What courses are your son/daughter currently taking? Do you feel like these courses will help your son/daughter when he/she gets out of school? Why or why not?
6. What kind of experiences has your son/daughter had? Has he/she been integrated with same-age peers? Does he/she participate in community experiences at school and/or at home? What type of employment training is your son/daughter receiving? What job situations have your son/daughter explored? How do you feel about this?
7. Does your son/daughter have goals on his/her IEP that included employment, post-school adult living objectives, and/or daily living skills? If so, do you feel like you were involved in developing these goals?
8. Does the school have an IEP meeting every year for your son/daughter? Do the goals for your son/daughter change from year to year? If so, how can you tell your son/daughter is making progress on his/her goals?
9. How often have you attended your son/daughter's IEP meetings? Describe what the IEP meeting was like for you/your family. Was this a positive or negative experience for you and your family? Why? How do you feel you were involved in the meeting? Did anything happen during your son/daughter's IEP meetings that surprised you? If so, describe what happened.

10. Has anyone from the school invited your son/daughter to attend his/her IEP meetings? If so, has your son/daughter ever attended his/her IEP meeting? What was this experience like for him/her? For you? How was he/she involved in the meeting?
11. Do school personnel take steps to ensure that your son/daughter's preferences and interests are considered when developing his/her IEP? If so, how do you know if they are considering your son/daughter's preferences and interests? Do you feel like your son/daughter is able to participate in making decisions about his/her life after he/she leaves high school? What kinds of decisions do you think he/she should be able to make with regards to his/her life after high school?
12. Are you comfortable at your son/daughter's IEP meeting? What kinds of things make you comfortable at these IEP meetings? What kinds of things make you uncomfortable at these IEP meetings?
13. What kinds of supports and services will your son/daughter need when he/she leaves school? Do you know what supports and services are available for your son/daughter when he/she leaves school? If so, which ones do you know about? Have school personnel provided you with information about other agencies that can provide services to you and your son/daughter when he/she leaves the school system? If so, which ones? Did anyone from agencies outside the school system come to your son/daughter's IEP meeting? If so, how did you feel about having them at the IEP meeting?
14. What post-school goals do you have for your son/daughter? How do these differ from those presented by school personnel? Do the activities that your

son/daughter participates in at school promote movement from school to the desired post-school goals that you have for your son/daughter? If so, which activities?

15. Do you ever feel like you are not treated as an equal partner by school personnel in decision making in any school meetings? Describe some experiences when this has happened. Do you ever feel intimidated by school personnel when you attend school meetings or conferences? If so, what has made you feel this way? Do you ever feel like your son/daughter's school personnel do not respect your beliefs and values with regards to your son/daughter's future? What are some examples of when this has happened? How do you make your wants and wishes for your son/daughter's future life known to school personnel?

The third interview encouraged the participants to reflect on the meanings behind their experiences. Making meaning of these experiences requires participants to look at the factors that have brought them to their present situation, to assess their present experiences and the context in which they have occurred, and to reflect on what they might experience in the future (Seidman, 2006). The questions in this interview took a future orientation and were influenced by the data gathered in the first two interviews. These questions included the following:

1. What are your son/daughter's dreams for his/her future life? How do you think you can support your son/daughter in reaching his/her dreams for the future?
2. What are your dreams for your son/daughter's future life? What are the steps needed to move towards making your son/daughter's and your family's dreams a reality?

3. What age do you think your child should be finished with high school? Are you aware that your son/daughter can receive services from the school district until he/she turns 21 years old?
4. Do you hope to see your son/daughter work after high school? If so, what type of work experiences (such as competitive, supported, or sheltered employment) do you hope to see your child in after he/she graduates from high school?
5. Do you hope to see your son/daughter have post-secondary educational experiences after high school (such as taking courses at a community college, work-training courses/programs, college courses, and continuing education)? If so, what type of educational experiences do you hope to see your child have after he/she graduates from high school?
6. Where do you hope your son/daughter will live when he/she is an adult? Do you see him/her living with someone other than you? If so, who? When might this happen?
7. Who will be responsible for caring for your son/daughter when you are no longer able to care for him/her? What steps have you gone through in order to ensure that he/she will be cared for when you are no longer able to care for him/her?
8. What will his/her life be like when he/she gets out of school? Describe what a typical day will be like for your son/daughter when he/she is done with school?
9. Do you hope your son/daughter will participate in community activities when he/she is no longer in school? If so, what type of activities (such as clubs, common interest groups, community centers, going out with friends, church or

religious groups, voting or political groups, etc.) do you see him/her participating in? If so, how will he/she get to these activities?

10. What supports or services might be helpful for you and your family when your son/daughter leaves school? Do you think that you will get these supports from your family or from agencies in your town?
11. In what ways will your son/daughter's movement from school child to young adult be important for your own well-being? For the well-being of your family?
12. What kinds of things can go wrong in this movement from school to adulthood that will make things more difficult for you and your family? What will need to happen during this time to reduce your stress and improve the well-being of your family?
13. What would your life be like if your son or daughter with a disability were no longer living at home? What would you look forward to? What might bother you?
14. Think about the services that your son/daughter has received from school in the past, what would you change about the services that the school has provided to your son/daughter during this time of his/her life? In the future what would you want these services to be like?
15. After participating in this discussion, what do you think are the most important aspects of the movement from school child to young adult for your son/daughter?

Fieldnotes and Memos. According to Schwandt (2001), there is no set definition of fieldnotes although they have been described as “a kind of evidence on which inquirers base claims about meaning and understanding” (p. 96). In this study I made fieldnotes while conducting interviews and as a process of reflection on the interview process.

These fieldnotes covered such things as the transcript of conversations and interviews, audiotapes, copies of IEP/ITP documents, and research field journals or memos.

Memos are a written account of the analysis or directions for the analysis. These written records included progress of the study, feelings of the researcher, the researcher's thoughts regarding the study, and future directions of the research process. According to Strauss and Corbin (1998) they help the analyst move from working with the data to conceptualizing the findings. I used the memo writing process to provide focus to the analysis process. Along with memo writing, I made a computer file for each participant that contained interview transcripts, memos, my thoughts recorded following each interview, and any charts developed from the data analysis process.

Document Review. Document analysis refers to the process of analyzing and interpreting data gathered from the examination of documents relevant to the topic of the study (Schwandt, 2001). This review of documents was used to support data collected during interviews and observations (Yin, 1994). Each participant was asked to provide a copy of his or her child's individual education plan or individual transition plan (ITP) to the researcher. ITPs were reviewed and analyzed in order to determine the transition services being provided to each participant's child. The analysis of these documents was then compared to the expectations of the parents to determine if there were any discrepancies between school services and parent expectations. Collection of this data were intended to answer the following research questions: In relation to program documentation (e.g., IEP/ITP), how do parent expectations for their children and their description of the services their children need differ from those being provided by the school program?

Demographic Data. Demographic data were collected on each participant in the study through the use of a questionnaire (see Appendix D). Participants were given this demographic form to fill out at the time of the first interview. Data collected through this questionnaire were used for descriptive purposes.

Data Analysis

As noted previously, in grounded theory, there is no clear separation between data collection and data analysis. This means that, as a researcher, I was gathering data, reflecting on the process, transcribing records, and revising my understanding of results as I progressed through this study. This process is reflective in the description of data analysis that is provided below.

Qualitative research produces an enormous amount of data to be managed, sorted, and analyzed. Seidman (2006) suggests that the process of data management should be carefully contemplated before the data collection process begins.

In grounded theory data are organized through a multi-step process of data coding. The researcher transcribed interviews and coded the data as they were collected. The researcher then examined each line of data and defined it relative to the content of the data. This line-by-line coding process helped to provide a perspective on the data and guided further data collection. It also helped the researcher to be aware of how each participant viewed his or her experiences, and helped the researcher avoid imposing his or her own interpretations on these data. This coding process produced a larger conceptual framework as the coded lines were combined into larger categories (Charmaz, 2000).

Constant comparative methods were then utilized to make comparisons between different views, situations, experiences, and accounts. These comparisons took place within the same individual at different points in time, comparing one incident with another, comparing specific data with a particular category of data, and comparing one category with other categories of data (Charmaz, 2000).

Coding is the process of disaggregating the data, breaking it down into smaller segments, and naming these segments (Schwandt, 2001). In accordance with grounded theory, after transcribing each interview, I used open, axial, and selective coding to organize the data into categories (Corbin & Strauss, 1990). Open coding was used to break-up the data so categories could be developed. First, transcripts, fieldnotes, and documents were examined for salient categories of information supported in this data. I coded the interviews line by line identifying themes and related content. I then color coded the interview data so that each category could be easily identified within the entire transcript.

Once initial categories had been developed, axial coding was performed. This process first identified one category as a central phenomenon and then related identified categories back to the central phenomenon (Creswell, 1998). Axial coding puts the data back together by exploring the interrelationship among each of the categories and subcategories. During this process I utilized theoretical sampling to compare data from each participant to find gaps in the categories. Categories were compared and contrasted until no new categories were identified. Criteria for identifying new categories included the number of times the category was found in the data, the number of cases in which the category was found, the implication of the category to a more general theory, the ability

of the category to relate to all other emerging categories, and the level to which the category allowed for variability (Strauss & Corbin, 1998). During this phase of analysis, a coding chart was created to visually display the interrelationship of these categories of information.

Selective coding was the final phase of coding in the data analysis process. The selective coding process validates the relationships identified between the central phenomenon and other identified categories. Selective coding also fills in categories that need further refinement and development (Strauss & Corbin, 1990). In selective coding, I refined and integrated the theory. This integrative process consisted of organizing the interview data and memos into the six components of grounded theory. Strauss and Corbin (1990) have identified these components as the causal conditions, the central phenomena, intervening conditions, the context, action/interaction strategies, and the consequences resulting from the action/interaction strategies. Causal conditions are the categories of conditions identified that have influenced the central phenomenon to occur. The central phenomenon or central category is the formation of the visual theory, model, or paradigm. Intervening conditions are the broader conditions within which the strategies occur. These conditions might influence the strategies in response to the central phenomenon. The context is the particular set of conditions within which the strategies occur. Action/interaction strategies are the specific actions or interactions that occur as a result of the central phenomenon. Consequences are the outcomes of strategies taken by participants in the study. These components were portrayed in a visual diagram called a coding paradigm. This diagram was drawn with boxes and arrows indicating the process

or flow of activities. This process led to building a story connecting the categories that were developed into a theoretical model (Creswell, 1998).

Qualitative Research Rigor

Qualitative research addresses the concerns of measuring validity and reliability of the findings through the concepts of dependability, transferability and, trustworthiness (Creswell, 1998; Lincoln & Guba, 1985; Merriam, 1998). Dependability reflects the reliability of research and whether the findings are consistent with the data. It ensures that the research process is well documented so that it is traceable and can be determined as logical (Schwandt, 2001). Methods to maintain dependability include triangulation, peer examination, and audit trail.

Transferability determines how well the research findings can be applied by the reader. The reader determines whether or not the findings apply to him/her on a case by case basis. The use of rich, thick description in this study ensures that the reader will be able to determine if the findings can be transferred to other situations. Rich, thick description of the data and context of the study were provided to ensure that the reader is able to determine how closely it matches other situations. The reader can then decide to what extent the results of this study can be transferred to his or her situation (Merriam, 1998). In the final results, I have included detailed quotes from the interview data and document analysis to provide the needed details for reader transferability.

Research is trustworthy to the extent that the researcher has accounted for the reliability and validity of the information presented to the reader (Merriam, 1998). Several strategies can be used to ensure trustworthiness of the research and findings. The

following methods were used in this study: researcher stance, triangulation, member checks, and peer and expert reviews.

Researcher Stance

Clarifying the researcher bias from the beginning of the study is essential so that the reader understands the researcher's assumptions and position, which may have an influence on the study (Merriam, 1998). In this chapter, I have now identified my theoretical orientation, my worldviews, past experiences with this topic, and biases that have likely shaped the interpretation and approach that I brought to this study. I have also used a research journal to reflect on my thoughts, feelings, and experiences during the research process.

Triangulation

Triangulation is a process used to ensure integrity of the findings of a study. This process involves the use of multiple data sources, researchers, theoretical perspectives, and/or methods to confirm the findings (Schwandt, 2001). I have interviewed multiple participants; observed them, their home environments, and their interactions with other family members during these interviews; and analyzed documents as a means of triangulating the data. In addition, the findings of this study were more accurate and provided a more holistic understanding of participants perspectives because they were based on multiple interviews collected over a period of time rather than a one shot interview (Seidman, 2006).

Member Checks

In qualitative research, data and the interpretations of the data are taken back to the participants to ensure accuracy (Merriam, 1998). Member checks are used for

soliciting feedback from participants on the researcher's findings (Schwandt, 2001). This process allows participants to review and judge the accuracy and credibility of the findings of the study (Creswell, 1998). The participants of this study received copies of their interview transcripts and category charts for their review and feedback. Participants' feedback was solicited on use of language and/or interpretations of what was said during their interviews.

Peer and Expert Review

Peer review is simply asking a colleague who is knowledgeable to verify the findings of the study as they develop (Merriam, 1998). This process is similar to inter-rater reliability in quantitative research in that a peer reviewer questions the methods, meanings, and interpretations of the study. The peer reviewer allows the researcher to process feelings and experiences related to the inquiry process (Creswell, 1998). The peer reviewer for this study was an individual experienced with qualitative research. She was asked to review the transcription codes and categories, and verify their fit with the interview data. She was also asked to identify any overlooked categories or discrepancies in the coding process and verify category saturation.

Expert review is similar to peer review in that it allows the researcher to verify findings and interpretations with an objective person. For this study, the research advisor filled this role by reviewing transcripts, category charts, and providing consultation when needed throughout the research process to ensure the quality of analysis and final results. In addition, a language expert was used in the review of interview questions and transcripts in order to ensure correct translation and interpretation of the responses of those participants that had a primary language other than English.

Audit Trail

The audit trail is a systematically maintained documentation system that includes the decisions that are made throughout the research process. It consisted of the data collected in the study, explanations of concepts, and models that were developed. It also included journal reflections, memos, copies of letters to participants, e-mail discussions with the research advisor and peer reviewer, a detailed description of the procedures used to generate and analyze data, and a statement of the research findings (Schwandt, 2001).

Summary

This study employed a grounded theory methodology to investigate the perspectives of parents who are culturally diverse on the transition process of their children who have significant disabilities. As described previously, grounded theory involves conducting research and developing theory simultaneously. Based on the review of the literature, grounded theory methodology and a collective case study method were most appropriate for this research.

Using primarily interviews, multiple attempts were made to gather data through a process of theoretical sampling. This sampling process aided in the development of categories, and connected these categories through the use of a constant comparison method of data analysis. Data were broken up into different categories through the use of open, axial, and selective coding procedures. The developing theory was then presented at the end of the study as a logical diagram that represents the perspectives of each participant and provides a framework for understanding and explaining their experiences in the transition process. Finally, the trustworthiness, dependability, and transferability of this study were ensured through a variety of different techniques.

Grounded theory is designed to not only facilitate an understanding of the participants within the research but it also lays the groundwork for other research. The next chapter, Chapter IV, provides stories of the families who participated in this study. These accounts provide key details regarding the development of parental perspectives and expectations throughout the process of transitioning their children with significant disabilities out of the school system and into the adult world.

CHAPTER IV

FAMILY STORIES

This chapter presents the stories of the five families who participated in this study. Families included were carefully chosen using the selection criteria discussed in Chapter III (see Table 1). These stories contain detailed information of each family's experiences as they journeyed towards the transition of their child with significant disabilities out of the public school setting. These descriptions provide key details of the development of parental perspectives and expectations about the transition process.

Table 1

Demographic Information of Participants Matching Selection Criteria

Mothers	Children	Ethnicity	Age	Disability Label
Maria	Esperanza	Hispanic	20	Multiple Disabilities
Karina	César	Peruvian	21	Multiple Disabilities
Latoya	Jamar	African American	16	Autism
Rosa	Celina	Hispanic	18	Down Syndrome
Nina	Koda	Native American	18	Mental Retardation

These stories were constructed out of the data collected through the multiple face-to-face interviews, observations while in the families' homes, demographic sheets filled out by the participants, and IEP document reviews. Throughout this chapter, most of the information presented was taken from the interviews with the mothers. Whenever information is reported that refers specifically to a teacher and/or IEP team, it came directly from the IEP documents.

Coffey and Atkinson (1996) stated that a good story must include, "a beginning, a middle, and an end" (p. 55). These stories describe significant points in time during these families' lives: from the parents' experiences growing up, to the discovery of their child's disability (beginning); their experiences and struggles with the school system, and their experiences with the transition process (middle); and the future plans for their child's life into adulthood (end). The narratives described in these stories provide the basis for the findings and subsequent theory construction described in Chapter V.

The Story of Esperanza

This is the story of Esperanza told by her mother Maria. Maria is a strong, dedicated Hispanic woman, focused on providing the best possible life for Esperanza. She is a loving wife, mother, and daughter who focuses her efforts on developing and maintaining a stable and loving home life for her family. She values educational opportunities, friendships, and being a contributing member of her community. Although, life for Maria was not always easy, she appreciates the trials that she has had to overcome because they have made her the person she is today.

In the Beginning

Maria, Esperanza's mom, was born in a metropolitan area of a large western city in the United States. She lived in the same house throughout her entire childhood with her father, mother, and two brothers. Maria's parents always provided her with a loving, stable home life. Because of this, Maria feels like she has always had the support from her family to deal with the challenges in her life.

Childhood Memories. Maria remembers having a great childhood, playing with her brothers and cousins in the evenings after school and on the weekends. Her family had very strong ties and would get together often with extended family to celebrate birthdays, holidays, and other important events. During these family gatherings, the women would cook many delicious, authentic Mexican dishes, the children would play games, and the men would sit around the table and talk about work and the good old days. Summer was especially enjoyable because Maria and her brothers would spend even more time with their extended family while their parents were at work. Her parents would also take them fishing during the summer, which was something that the family really enjoyed doing together.

Even though both of Maria's parents spoke Spanish, her father refused to teach Spanish to his children, saying he wanted them to be successful and believed that only by speaking English could they meet this expectation. With that same vision of success, employment was also an important value in her family. Both her parents worked full time, and Maria started working when she was only 13 years old, continuing to work through the time she was in high school.

School Memories. In addition to speaking English, education was important in Maria's family. Maria remembers that her father always pushed her and her brothers when it came to school, setting expectations that they all attend college. He made sure she did her homework everyday and he even made her take extra classes during the summer. Of course she didn't like this as a child but looking back she knows that this helped her to earn six scholarships when she graduated from high school. Interestingly, Maria found out while she was in high school that her mother could not read or write. She believes that this may be the reason her parents pushed her in school so much.

Maria went to college but transferred to several different schools along the way and ended up taking a break from school to work and get married. Soon after leaving school Maria found out that she was pregnant. She was very excited and scared of the unknown, which is typical for most first time mothers.

Becoming a Parent. When Esperanza was born and Maria and her husband were told that Esperanza was medically fragile and would only live for a short time, the excitement of being new parents quickly disappeared. Scared about the uncertainty of the future, Maria's life changed completely after Esperanza was born. She quit her job to take care of this baby with so many challenges, but this was only the beginning of their story; more struggles were yet to come. What followed were years of ongoing medical treatment, moving in and out of Children's Hospital, and fighting for their daughter's survival.

When Esperanza was two, her parents had a son. Maria recalls, "*We lived in the hospital so much during the time that my son was growing up that he called it home. He thought that this was how every family lived.*" This was a very difficult time in their

family's life and Maria feels as if the medical system did not provide the best care to her daughter. Maria said,

It was really hard because the nurses and doctors were always very negative. They were always telling me that Esperanza was not going to amount to anything, that she was going to be a vegetable, and that she was not going to be able to walk or talk or think.

They had very low expectations for her daughter and this was very frustrating for Maria because she wanted more.

The School Years

Up until the time Esperanza was 9 years old her parents fought for her health and they moved in and out of the hospital during much of that time. Because Esperanza had not attended school during these early years; she struggled with appropriate behavior and was very far behind socially and academically for her age. However, they eventually were able to enroll her in a center-based program at her neighborhood school.

Elementary School. Beginning in the third grade, Esperanza attended school full-time and was very excited that she was able to go to school with her friends that lived in her neighborhood. This meant that she attended general education classes and was only pulled out of class to receive specialized services when necessary. Esperanza was very good at imitating behavior of the people she was around, which is why Maria really pushed for her to have typical peer interactions while she was in school. Given this ability, Maria was convinced that her daughter could learn more age-appropriate behaviors by observing her classmates without disabilities. Esperanza loved to play computer games, watch movies, and look at books. Her mother described her as a “*great kid with a beautiful smile.*”

One day when Esperanza was in the fourth grade, an event took place at school that would change her life forever. As a consequence for refusing to eat, Esperanza's teacher decided to use restraint to put her into time out. This involved strapping her into her stroller, which was intended for transportation over long distances. The stroller was then pushed into a closet. Somehow, the stroller tipped over causing Esperanza to sustain a traumatic brain injury. As a result of this event, Esperanza was diagnosed with Post Traumatic Stress Disorder (PTSD) and became a totally different person. Her repertoire of behaviors changed substantially to include hitting, grabbing, pinching, and screaming. She would also bang her head on the walls and the floor resulting in self injury. In addition, she began having outbursts of aggressive behaviors, sometimes lasting for hours at a time, when frustrated. Esperanza's parents sued the school district and moved out of town in order to help their daughter start over. Unfortunately, even though they moved, this did not eliminate the negative attitudes that faced this family within the school system.

Middle School. The day that Maria went to take Esperanza to her new neighborhood school, she went in and told them that her daughter had a disability and was on an IEP. She recalls, "*[the school staff] almost freaked out because this school was one of the highest academic schools in the area and the students with disabilities were all bused to a center-based school.*" Frustrated, Maria would not allow her daughter to be bused to a different school. Their family had just moved to the area and she wanted her children to get to know the other children in the neighborhood so they would have friends close to their home.

Esperanza had developed some great friendships when she was in elementary school. However, when she got to middle school things got harder as her problem behaviors increased and intensified. Because of these behaviors many of the service providers refused to work with Esperanza. Things eventually got so bad that the educational team moved Esperanza up to the high school earlier than usual.

Through all of this, Esperanza's inappropriate behaviors continued to increase. She refused to be G-Tube fed, refused to have daily care given to her (changing her clothes, showering, toileting, etc.), and frequently ran away from her care providers. Many of these behaviors developed as coping mechanisms resulting from her experiences in the medical arena for a large portion of her young life. However, Maria feels like she unintentionally reinforced Esperanza's behaviors as her own way of surviving the stressful times.

The difficulties of raising a daughter with multiple disabilities placed a lot of stress on Esperanza's parents. The strain of dealing with the negativity in both the medical and educational fields caused marital issues between Esperanza's parents who eventually divorced.

High School. According to Maria, the teacher at the high school was very good and wanted to work with Esperanza, but unfortunately she moved away leaving Esperanza's family devastated. As a result of Esperanza's behavioral and medical issues eventually the school was not able to find anyone who was willing to provide her services. Although the school was willing to pay for an out of district placement in a residential facility, Maria was totally against this type of placement, and thus, the only other option was for Esperanza to be provided services as a homebound student. The

school district told Maria that if she would start working on her teaching degree in Special Education, they would be willing to hire her to be Esperanza's primary service provider. She would work under the direction of the school district's transition program teacher at the high school that Esperanza would attend if she went to school. She agreed to this arrangement and it has been in place for the last three years.

Esperanza is now an affectionate, happy young woman who likes to smile and is very good at making herself known, which can be good and bad. It is good because she is able to take control of her environment and use self-determination skills to make choices when given pictures. However, Esperanza has limited communication skills with only a few functional vocabulary words, and since she is not able to communicate effectively she often becomes frustrated and acts out.

Esperanza's Transition Program

Esperanza will soon be turning 21 years old, which means that this is the last year she will receive services from the public school system; although, Maria is still providing all of her services. Esperanza began this school year with a transition plan in place for life after high school with goals that included working on independence and developing skills for daily living. Specifically, Esperanza's goals involved (a) accessing different venues in her community such as going to a restaurant, ordering, and paying for her food; (b) taking the public transportation system with a support person other than her mother, (c) continuing to access her computer program that focuses on literacy skills, and (d) completing the routine for daily living three times a day with increased independence.

At home Maria tries to work with Esperanza on increasing her independence when it comes to daily living skills. Although Esperanza needs total care for all of her

daily needs, she is able to help with dressing and bathing herself to a limited extent.

Maria also tries to get Esperanza out in the community at least once a day by going to the store and picking out items that she needs. Yet, a big concern for Maria is the fact that Esperanza is so dependent on her. Maria would like Esperanza to learn to tolerate support from other people. She has set up a schedule where Maria's brother, father, and grandmother will provide some of Esperanza's 24 hour, seven days a week care so that Maria can get a short break.

Several times a week the school's community based transition program when somewhere on a field trip. They went bowling, skiing, and swimming and took outings to the museum and zoo. Maria tried to get Esperanza involved in these outings but many times Esperanza either refused to get out of the car or would not participate once she was with the other students. Often her behaviors worsened when she was in large groups of people or where there was a lot of noise. The transition program also made other outings, such as visiting different community college campuses, attending job fairs, and going to different job sites. However, Maria did not have Esperanza attend these types of outings. She said that she had her do the things she knew that Esperanza would enjoy.

Unfortunately, life will not be much different for Esperanza once she leaves the school system. Because Maria is currently providing all services to Esperanza, this pattern of service provision will continue into the adult agency arena once she finishes this school year. Maria has expressed the fact that she feels trapped in this situation and feels like she let the school off the hook. She would rather have seen the school educate her daughter the way that it was supposed to so that she could have a life and work to support her family the right way.

Esperanza's Future

Currently Esperanza is living at home with her mother, her maternal grandmother, her cousin, and her step-father. As Esperanza transitions into adulthood, supports have been put in place to help her family care for her into the future, although Maria feels that the post-school options for Esperanza are limited. The post-school supports that are currently in place simply provide funding to pay for some assistance in the home that she will need once school ends. Esperanza will be receiving Supplemental Security Income (SSI) benefits, and she is eligible for Medicaid. She will also receive funding for Personal Assistance Services through the local community center board. This will pay for someone to care for her 3-½ hours per day. However, because Esperanza will not allow anyone to care for her besides her immediate family, it is likely that no new people will be a part of her life. This has left a feeling of isolation and seclusion as her family looks into the future.

Esperanza is on a waiting list for residential services, as a safety net if the family were no longer able to care for her. Maria has stated that she would not be able to imagine Esperanza living outside of the family home. The main dreams that Maria has for Esperanza's future are that she could be more independent from her and that she could be able to communicate more with other people. She would also like for her to make friends and have people her own age to do things with. She doesn't want her to just stay home and have no friends. Ultimately, her dream for Esperanza is for her to be happy.

The Story of César

This is the story of César told by his mother Karina. Karina is a soft spoken, gentle Peruvian woman, dedicated to fostering a loving and enjoyable life for her family. Although she works full time outside of the family home, her husband and children are her most cherished responsibility. She also values extended family relationships, participation in recreation and leisure activities, and being able to take part in educational opportunities. Karina's current life is not what she anticipated for herself when she was growing up. However, she has come to accept and treasure the experiences and opportunities she has been given.

In the Beginning

Karina, César's mom, was born in a large city in central Peru. Her parents divorced when she was very young and, although she saw both of her parents on a regular basis, she lived mainly with her mom. Karina was the youngest of her five siblings. In fact, all but one of her siblings had moved out of the family home by the time she was born. Despite this fact, she had a very close family unit that served as a support system throughout her childhood.

Childhood Memories. Even though Karina's brothers and sisters were much older than she was, Karina remembers spending a lot of time with them when she was growing up. She recalls that her mom worked all of the time and Karina would often stay with her older sisters while her mom was at work. She remembers enjoying going out to lunch and doing the shopping with her sisters. Their family would also get together often on the weekends to spend time together. Growing up in a religious family, Karina attended church services on a regular weekly basis. This was something that her family

did together every single week. They also enjoyed participating in activities such as playing soccer and going swimming. Holidays, such as Easter and Christmas, were especially enjoyable and memorable events in Karina's childhood. These were a very important part of her family's religious beliefs, and they would celebrate these events for several days. Being raised primarily in a lower income, single parent home for the majority of her life, Karina's mother performed most of the household duties without the help of hired workers. Karina recalls that her mother was a meticulous housekeeper, and at a very young age Karina was expected to help with all the household duties, something that she did not like when she was a child but looking back now she can see how this instilled her with a good work ethic.

School Memories. Education was highly valued in Karina's family when she was growing up. Her parents believed that in order to be successful in life, a good education was required. In Peru, a good education was not something that every child had the privilege to receive. Families that could afford it enrolled their children in private Catholic schools. Karina recalls that she did very well in school, which was something that made her parents very proud. She was even able to attend college after she graduated, something that was highly respected within the structure of Peruvian society.

César's father also grew up in Peru. He and Karina met while they both attended college in Peru, receiving degrees in business and accounting. They had not been married long when they found out that Karina was pregnant with their first child. Of course, they were very excited to find out that their baby was going to be a boy, who would carry on the family name.

Becoming a Parent. When C  zar was born in Peru, he was purple from swallowing amniotic fluid and was placed in an incubator for 10 days due to hypoglycemia. After C  zar came home from the hospital, Karina received a lot of help from her mom and her mother-in-law. She also had a nanny who helped her take care of C  zar when he was a baby and maids who cooked and cleaned the house, which are common Peruvian practices among the upper and middle classes.

Since C  zar was Karina's first baby she did not realize that he was not developing normally. During a routine check-up, the doctor told her that her son was "dumb." Karina and her husband were shocked. Karina recalls that there were a lot of "whys" and that this news was hard for them to accept. After they had some time to process this information, and after talking with their friends, they were able to accept that their son wasn't normal. Also, their priest provided a great deal of comfort when he told them that they had been selected to raise this special child.

At that time, there were not many services in Peru for children like C  zar. However, he did receive some therapy at the hospital to help him learn to walk, which he accomplished by age 2-1/2. However, Karina and her husband realized that their child was not going to be included in Peruvian society, so they decided to move to the United States. They believed that in the U.S., their son could receive better medical and educational services. They also wanted to have more children, and the doctors in Peru were not able to tell them if C  zar's issues were genetic. They believed that doctors in the U.S. would help them find out if they should have any more children.

Life in the U.S brought many opportunities as well as challenges. C  zar received many services that increased his quality of life as well as the quality of life of the family.

They also found out that C  zar's disability was not genetic so they were able to have more children. In spite of the fact that both Katrina and her husband had college degrees from Peru, their degrees were not recognized in the U.S. business world. Although relocating to the United States was a huge cultural adjustment for them, they were so happy that they had the opportunity to provide their son with a better life than what was available to him in Peru.

The School Years

C  zar was an extremely happy, young child who was very loved by his family. He learned new skills quickly, with lots of repetition, but it took some time for him to change routines or get used to new ones. He enjoyed playing with his cars, listening to music, and watching videos.

Elementary School. C  zar attended elementary school near his home. For the first several years of his schooling, things were good. He was instructed primarily in English when he was at school, but continued to hear and speak Spanish with his family at home. He was able to participate in his special education class as well as some non-academic general education classes such as P.E., Art, and Music. He learned how to be more independent in spite of requiring full-time support, and he learned to perform small tasks with direction from a paraprofessional.

Unfortunately, C  zar exhibited some problematic behaviors. He was significantly hyperactive. He would exhibit the following behaviors: clapping his hands, biting his hands, tactile defensiveness, and preservation in his play. He also had sensorimotor integration problems. However, aggression was the most problematic behavior for him both at school and at home. When frustrated, C  zar would become very irritable and

would grab, hit, or pinch whoever was close to him. Fortunately, these behaviors did not seem to be a big deal from kindergarten through his fourth grade.

The summer after C  zar finished fourth grade his family decided to move to a bigger house since they needed more room to accommodate the additional children they had. This move meant C  zar would be attending school in a different district. When he went to his new school, they were not prepared to educate him even though Karina called them long before the start of school. Karina recalls,

Every single person assigned to provide services to my son told me that they could not work with him. They said he could not sit for more than twenty-minutes, that he could not do anything, and that he was so dangerous that he should not be around the other children and the teachers

They sent him home right away and it took his parents two years of fighting with the school district to get him back into school.

Middle School. The new school district wanted to place him in a special school or provide homebound services to him, but Karina said that she did not like the special school and the way they treated the children. Karina and her husband would like to have sued the school district, but they did not have the money to hire a private lawyer. Thus, it was easy for the school district to dismiss them. C  zar missed the next two years of school and finally his parents decided to move again so that he could go to school in the first school district that he attended. By this time, C  zar should have been entering the seventh grade; however, his behaviors had gotten much worse since he had not been in school for so long, and it was much harder to have him at school. Now, the educational team decided that it would be best for C  zar to be moved up to the transition program early. They felt this placement would be much better for him since there were less academic constraints placed on him there.

High School. As noted above, C  zar was already in a transition program for students age 18-21 at the age of 12 years old. C  zar’s parents agreed to this arrangement because they wanted their son to receive an education and because having him at home placed a huge financial burden on their family. Karina said, *“Ever since we moved him to the transition program, things have been fine. They want to work with him there. They are willing to work with me as well.”* Even though they were not really accomplishing much with him through the transition program, it was enough for her to see that they were happy to work with her son. In light of their previous problems with the school system, Katrina and her husband were content with what they were getting from the transition program.

C  zar’s Transition Program

C  zar just turned 21 years old, and he is preparing to transition out of the school system very soon. His transition goals included: (a) improving his ability to work and learn in the community and other natural environments, (b) improving his safety out in the community, and (c) engaging in social and recreational activities with others in order to establish relationships. In order to reach these goals, C  zar has participated in a number of different activities. He has been working on completing small work tasks at his desk with increased independence. He also is an active participant in a cooking class, hobby club, and swimming. C  zar attends a daily living class, work skills class, and participates in volunteer opportunities in the community.

For the last few months he has been getting out in the community more. He has been sharing time between the school’s transition program and a privately run community-based program. The school’s transition program meets at the district building

and the students go to different places in the community. Students in this program learn functional skills such as crossing the street, taking the bus, and going to a baseball game and paying for their tickets. They learn vocational skills and César has participated in some work experiences at a restaurant and a grocery store with support. They also learn recreational skills, and he participates in a craft class everyday. Throughout all of these activities, César's mom reports that he requires extensive support, and a variety of people will work with him.

César participates in the privately run community-based program two days a week. The activities provided through this program include swimming, bowling, watching movies, going to the mall, going out to eat, and shopping at the grocery store followed by a cooking class. He does really well with this group and his family would like for him to be able to go more than two days a week, but unfortunately they don't have the money to pay for any more days.

Karina is happy that the school is working with César to be more independent but she has limited expectations for him to live on his own or hold a job, and there are many skills the school is working on that she and her husband do not value or see as important. César's IEP team wants him to improve his community access skills, such as learning how to cross the street at an intersection with a traffic light by pushing the signal button and waiting to walk until the appropriate time as well as learning to ride the public transportation system. However, his family does not use public transportation and they do not feel like this is something he will use once he leaves the school system. At school, César practices using a fork and spoon when eating lunch and snacks, and he is somewhat successful with this. Yet according to the IEP, his teacher has expressed that

being fed at home appears to be inhibiting his overall independence in this area. Karina says that she likes to feed C  zar because this is really the only time she has interactions with him during the days he is at school.

C  zar’s IEP team feels that communication is also an area in which he needs to continue to improve. His primary language and the primary language spoken in his home is Spanish; however, he is spoken to in English at school. Despite this, C  zar is successfully able to communicate at school using a communication book, hand over hand requests, vocalizations, and gestures. At home, he also uses gestures and vocalizations, but does not use any formal communication system such as pictures. Although C  zar’s family does not always see the importance of the activities he participates in at school, they are very happy that he is able to receive services from the school.

C  zar is a very happy young man, dearly loved by his family. C  zar’s parents describe him as their “*big boy*” and “*their little angel*.” They see him as “*special*” and believe that he is going to live with them for the rest of his life. His parents do not see his disability as something that needs to be fixed. They accept him the way he is and enjoy the opportunities they have to spend time with him. He loves going for walks, especially outdoors, and watching movies such as *Cars* and *The Fast and the Furious*. In fact, C  zar likes cars so much that he will touch them as he walks by parked cars.

C  zar’s Future

C  zar continues to live at home with his dad, mom, and three younger sisters. Karina has expressed her fears for the future and feels like there are limited post-school options out there for children like her son because of his need for constant support and supervision. They have looked at several different day programs but feel like these have

not met their expectations. Karina said, *“I cannot see my son sitting in a room with a bunch of people doing crafts all day.”* As the time for C  zar to leave the school system grows closer, things have become more stressful for his family. Because Karina and her husband have to work full time they do not feel like they have enough time to help C  zar participate in some of the available post-school options. For now, C  zar will continue to participate in the community-based program two days a week, and he will have to go to work with his dad on the other days. This is not an appropriate setting and could possibly jeopardize his job, but the family has no other option. C  zar is now on a waiting list for residential services, but Karina has stated that she does not want her son to leave home and that she worries about the time when she will no longer be able to care for him. C  zar’s parents’ dream is for him to be happy and to enjoy life.

The Story of Jamar

This is the story of Jamar told by his mother Latoya. Latoya is an independent, highly educated, successful African American woman, dedicated to ensuring that her sons receive every opportunity in life to achieve success. Although she is currently working full time, she has always been very involved in the lives of her children. Because both of her sons have disabilities, dealing with agencies including the school system has become an expected part of her everyday life. Her own education as well as the education of her children is one of her most valued treasures. She also values the opportunities that she has had to provide service to her community, to participate in recreational activities, and to develop close personal and professional friendships that provide her with support.

In the Beginning

Latoya, Jamar's mom, was born in a northeastern state in the United States. She grew up in a predominantly segregated African American neighborhood. After her parents divorced when she was only 4 year-old, Latoya lived with her mom and stepsister. Life has not always been easy for Latoya; however, she has always been able to succeed in life despite the barriers that have been placed in her path.

Childhood Memories. Things were very tough economically when Latoya was growing up. She recalls coming home and there being no food in the house. She also remembers watching her mom get upset because there was no money to pay the bills. Because no one was around to meet her needs much of the time, Latoya grew up with a sense of independence. From around the age of eight, she would come home after school and be at home alone for hours until her mom got home from work. Despite the fact that Latoya's mom came from a large family, she had been raised with a strong sense of independence, and she did not like to rely on other people. Although Latoya's extended family would get together to celebrate holidays, birthdays, and other important life events, they did not see each other on a regular basis.

School Memories. Growing up in the turbulent sixties and seventies with the educational problems of segregation and busing, Latoya's first memories of desegregation were when she was in the 3rd grade. The topic of education was a stressful and scary one for many African American families in Latoya's community, and education was not valued by Latoya's family when she was growing up. As a matter of fact, she does not recall her mom being an active participant in her education. Despite this, Latoya's mother decided to put her into a private school during high school because

the conditions in her public high school were very dangerous for African American students. Latoya recognizes that this was a huge sacrifice for her mother financially.

Although Latoya had planned to go to college immediately after graduating from high school, she met her future husband and decided to move out west with him to pursue their future. She held a variety of different jobs before she had her children but nothing that held permanence. Her husband was a general contractor for a company that performed residential remodeling and new construction, but it was not long before he decided to start his own business instead of working for other builders.

Becoming a Parent. Soon after they built their home, Latoya and her husband found out that she was pregnant with their first son. Latoya wanted to be a stay at home mom with her children, a decision she believes was influenced by the absence of her parents when she was growing up. Jamar was born two years later. He appeared to be a typically developing child until he was around 18 months old. At that point, he stopped responding to his name even though they knew he could hear because he would scream at other things. He started refusing to eat some foods and he lost skills in speech. Latoya took Jamar to the doctor and discussed these issues, but his doctor continued to reassure her that he was healthy and developing fine. However, on a trip to visit family, Latoya's mother-in-law observed Jamar's lack of engagement and interaction with the other children and told her that she thought something was wrong, which only confirmed her fears.

After visiting her mother-in-law, Latoya returned to the pediatrician and eventually received the diagnosis that her son had autism. Latoya tried to think back into her past to connect this with her previous experiences. This was a very difficult thing to

deal with and understand. The only thing she knew about kids like these were that they were placed in institutions, and that was not what she wanted for her son. Latoya felt that people looked at her son and said “if we fix certain things about him everything will be fine.” But she did not feel that her son needed to be fixed. When she looked at her son she saw him and his wonderful personality, not his disability.

While her children were younger, Latoya wanted to stay home and take care of them. She did not want to put her children in daycare, as she had been. However, this caused the family to struggle financially. Once her children got older though, Latoya decided that she wanted to go back to school, and because of the experiences with her sons, Latoya decided to learn more about the laws that govern special education services. She ended up graduating with her degree in Special Education Law and is now an attorney working for her local State Education Agency.

The School Years

Jamar was a very active, energetic child who loved to be outdoors. He had a very engaging personality that allowed him to get along with almost anyone. He learned new skills quickly, especially if they were presented to him in a visual way. He enjoyed going for runs and motorcycle riding with his dad.

Elementary School. When it was time for Jamar to go to school, Latoya decided that she would send him to his neighborhood school, and she also wanted him to be included in general education classes just like everyone else. As an African American mother who grew up during the time of segregation, she was not going to allow her son to be segregated based on his disability. This choice led to many years of fighting with the school district to obtain inclusion for her son. Her relationship with the school was

clearly adversarial and she recalls some degrading IEP meetings. However, the end result was that Jamar participated in general education throughout his elementary school years. Unfortunately, the school's idea of inclusion was to put him in a general education classroom with a full-time, one-on-one paraprofessional, and instead of modifying what the rest of the class was working on, Jamar was provided with a totally different curriculum. Latoya expressed her disappointment in the education that her son had received because she has seen successful inclusion for other students in other school districts and that was what she wanted for her son. Nevertheless, she does feel like having her son included was still a positive experience for him, because he learns best from watching others, and being around his typical peers has influenced his behavior in many positive ways.

Middle School. Despite pressure from the school district to place Jamar in a center-based program at the end of fifth grade, Latoya fought to keep him included in general education throughout his middle school years. A huge challenge for Jamar in school has been his behavior. He had become very aggressive at times; lashing out, hitting, chinning, and biting. He also had developed the tendency to wander away. In the past, he has left the school building and gone wondering out in the community. At one point, Latoya remembers the principal threatening to suspend Jamar and force a manifestation of determination so that the school could change his placement. Similar to when Jamar was in elementary school, there were times during Jamar's middle school years when things were very contentious between her and the school. However, by the time Jamar was in middle school, Latoya had begun working on her law degree in Special Education, which made her feel much more confident when dealing with the school

system. Looking back, she sees the difference that being in the general education environment has had on Jamar. She has heard comments from teachers and parents about the positive effect Jamar has had on them as well as on the other students. This would not have happened if she had not fought for inclusion.

High School. Unfortunately, inclusion was not an option in high school, and Latoya allowed him to be placed in a center-based, Life Skills Program for students with moderate to severe disabilities. However, he is included in general education classes that the school staff feel might be appropriate for him, which include P.E. and Walking. The Life Skills Program provides him with instruction in academics designed for younger children, daily living skills, communication skills, adaptive P.E. and behavioral supports. Jamar also receives a full-time, one-on-one paraprofessional who supervises him at all times.

Jamar participates in a Circle of Friends group at school. She knows that her son really enjoys these interactions and would love for her son to be involved in more activities or classes at school where he might be able to engage with typical peers. The P.E. teacher has commented that Jamar is a very good runner and it would be great if he could participate in the school's track team. This is something that Latoya would be very interested in Jamar participating in; however, he would have to have a one-on-one support person with him, and she would not be able to do it because of her work schedule. Latoya relays her feelings about having to give up on her dream of inclusion for her son, *"I just feel worn down by this system that is not effective or supportive. Although the school system has left me feeling hopeless, I do see a bright future for my son."*

Jamar's Transition Program

Jamar just turned 16 years old but has been receiving transition services since his last IEP meeting. At school, he is receiving transition services through the school district's employment team. They provide support for Jamar to participate in work experiences with the assistance of a job coach. He is also involved in some community programs outside of the school district. In addition, he has participated in some activities provided by the local community center board that provide students with disabilities the opportunity to engage in more recreational activities. Furthermore, he also participates in an after-school program that focuses on social skills development. However, comments have been made that Jamar might be too disabled to participate in this group.

Jamar's Individualized Transition Plan (ITP) contains goals related to improving his functional skills in several different areas. In order to reach this goal, Jamar participates in activities such as learning to use a calculator, identifying coins and their values, correctly identifying sight words, improving his ability to write short sentences and comprehend written material, and improving his independent skills while at school. Although Latoya likes the fact that her son is receiving some academic instruction in school, she feels as though the instruction is not individually modified to meet the needs of each student. The curriculum is modified the same for all of the students, and therefore, it is not taking into account the learning needs of her son. She does not really feel like the Special Education courses he is taking at school are going to help him once he leaves the school system. For years, Latoya has asked that the one-on-one paraprofessional support to be faded out of her son's educational program. However, the school refuses to remove this support, stating that he needs it because it is a safety issue.

Latoya feels that having a paraprofessional always hovering over her son every moment of the school day is interfering with his ability to develop typical peer relationships, which is causing him to become more and more reliant on adult support and interaction.

Another goal for Jamar is to improve his community skills by attending a Life Skills cooking class in which he learns to set the table, pour drinks, prepare food items, do the dishes, vacuum, and utilize good manners. He also participates in unpaid work experiences at three different locations. He stocks drinks in the school cafeteria, he does recycling at a local retirement home, and he folds pizza boxes at a nearby pizza place. While at work, Jamar is encouraged to initiate and respond to greetings and salutations with staff people at his place of employment. Although Latoya would like for her son to have a job once he is out of school, she would prefer that the work was not so repetitive and demeaning. She feels like the school has a limited number of resources when it comes to providing employment opportunities to the students in the Life Skills Program.

Another area that his IEP team would like him to improve is his ability to control his behavior when there are unexpected changes in his routine. Again, behavior is a major challenge for Jamar that in general, has improved over the past school year. Latoya wishes that the school had done a better job of teaching Jamar to self-regulate his behavior instead of implementing behavior plans that focused on punishment. She feels as if this approach would have helped her son to be able to control his own behavior instead of looking to an adult to set the limits on his behavior. The final goal for Jamar is to improve his functional communication and basic language skills in order to access information and express ideas. In order to meet this goal, he needs to work on initiating conversation, asking questions, making comments, and using more descriptive comments

when engaged in structured activities in the classroom. Again, Latoya lamented that the push for speech therapy and remedial speech instruction early on in her son's education should have been replaced with instruction in the use of alternative modes of communication, thereby providing her son with more efficient and effective ways to communicate. Unfortunately, at this point, she feels as though it is too late to go back and change things in these areas for her son.

Jamar's Future

Currently, Jamar is living at home with his mother, father, and older brother. He has a very supportive family who loves him and wants to see him become a successful adult. In two years, Jamar will be a senior in high school. Latoya would like for her son to walk through the graduation ceremony when he is a senior, since he knows many of the other students in his sophomore class given the fact that he was included in general education for the majority of his school career. However, she is concerned about doing this since the school district only provides employment support services after students have gone through graduation. She would prefer that he also be able to continue receiving some sort of academic instruction since her goal for him is to attend a post-secondary program designed for students with more significant disabilities.

Latoya has many goals for her son's future once he has left the school system. Not only does she want him to get a college experience and to have a meaningful job, but she would also like for him to be able to live in an apartment of his own someday. She wants him to be an active member of his community. She wants him to have friends and for people in his community to know him and care about what he is doing. Happiness is her ultimate dream for both of her children. However, the reality of the situation is that

society, including the school system, has very low expectations for individuals with significant disabilities. So she feels as if things might look different from what she would like. Latoya states, *“I feel as if the school district politely listens to my expectations and then privately disregards them as being inappropriate and too high.”* Unfortunately, she believes that if she is going to get the post-school outcomes that she wants for her son she is going to have to work on them herself without the help of the school.

The Story of Celina

This is the story of Celina told by her mother Rosa. Rosa is a hard working, strong-willed, Hispanic woman dedicated to making sure her children are provided with the things they need in order to have the best possible quality of life. Although currently struggling with health issues that have prevented her from participating in many of her usual activities, she has always been very involved in advocating for her children’s rights. Because several of her children have disabilities, understanding and collaborating with outside agencies and the school systems are a typical part of her day. Despite everything else in her life, her family is her number one priority. She values her religious beliefs and associations, working hard and providing service to other families with children who have disabilities, and opportunities to learn new things.

In the Beginning

Rosa, Celina’s mom, was born in a rural, southern town in a western state in the United States. Rosa grew up in a large, tight knit family. She lived with her father, mother, and six brothers and sisters. She had a very happy childhood even though there were periods of time when things were very stressful in her family life.

Childhood Memories. Rosa recalls getting together often with her large extended family to celebrate important family events. Because she lived in such a rural area, most of the people in her hometown were related to her in some way, so being around her extended family was an everyday occurrence. For most of Rosa's childhood she remembers her mother staying at home and taking care of her and her siblings. This was a great source of security for her, especially because her father was an alcoholic which led to many marital difficulties between her parents.

Unfortunately, her family had to move to a different part of the state due to limited employment in their hometown. Since most of their extended family was now living far away, they did not have the support system that they had grown accustomed to. This was a very difficult adjustment for her family. Employment was always something that has been valued in Rosa's family. Her father had consistent employment throughout the time she was growing up, and her mother eventually entered the workforce when Rosa was in high school. The children in Rosa's family were also expected to work at a young age. She recalls that she held a job since the time she was 16 years old until she had her first child several years later.

School Memories. The Catholic Church was a very important part of her family life when she was growing up and even though finances were tight, her parents somehow found a way to send all of their children to a private Catholic school. Attending a private Catholic school came with its own challenges. The school that Rosa attended, which was run by priests and nuns, was very strict. Because it cost so much to attend, many of the students came from very wealthy families and had an attitude of privilege. Rosa did not come from a wealthy family and experienced discrimination from her classmates because

of this fact. Despite the challenges, Rosa did very well in school, especially since she loved to learn about new things. Since she knew that her parents were sacrificing to send her there, she tried extremely hard to do the best she could in school.

Post-secondary education was not really something that was valued in Rosa's family. Rosa recalls,

College was not an expectation or a preference for the children in my family partly because there was not money to pay for it and also because my parent's generation of people had a fear that higher education would take their children away from them, and they would not be around anymore once they left and went to college.

Despite this fact, Rosa did attend college on a scholarship where she met her husband and they soon married. Her husband received his associate's degree in Industrial Management, and she went back to school after she had her children and earned her associate's degree in Early Childhood Education.

Becoming a Parent. One of Rosa and her husband's goals was to have a large family. Unfortunately, they could only have two biological children. Rosa stayed home with her two sons for a few years, but entered the workforce after going back to college. She held several jobs from directing a preschool program at a school for students with severe disabilities, to working for the State Department of Public Health and the State Department of Education as a family consultant. Then her husband decided to open his own printing business where she ended up going to work for him. Because they wanted more children, Rosa and her husband decided to do foster care through the department of social services. This was a great experience for them, and they ended up adopting two children, a boy and a girl, through this process. One of these adoptive children had a severe learning and communication disorder and the other one had Down Syndrome.

Adopting these children brought much joy into their lives but also had its challenges. They later adopted another little girl from Mexico and thought that they were done but they weren't. Over the next five years, they ended up adopting two more girls with Down Syndrome solely based on their positive experience with their first daughter who had the same disability. So all together, they have three boys and four girls in their family with more than half of their children having a disability. Rosa relates the joy that has come from having these children as part of their family. She shares,

Unlike other families that do not have a choice of having a child with a disability, we chose these children the way that they are and so typical feelings of having a child with a disability has not been part of our experience.

Currently, all of their children are adults except for the two youngest girls. Celina is 18 years old and is just finishing up her senior year of high school, and Marcella is 14 years old and will be moving to the high school next year. It has been quite a journey for them to get to this point in their education, and Rosa has said that she is happy the end is in sight. This case study narrative mainly focuses on Celina because she is currently receiving transition services through the public school system.

The School Years

Celina is a very social girl who is loved and adored by her mom as well as the rest of her family. She has always been very strong willed, and if she doesn't want to do something, nobody is going to make her do it. She loves to talk, but one can only understand about half of what she says. Because she is so strong headed, Rosa and her husband have had to learn to pick their battles when it comes to Celina.

Elementary School. Rosa has pushed for a fully inclusive program for both Celina and Marcella from the time they entered the public school system, and, for several

of their elementary years, they attended their neighborhood school where they were included in general education classrooms. The school district continually pushed Rosa and her husband to send their girls to a center-based program specifically designed for students with more significant disabilities, but Rosa refused to consider this option. Rosa recalls,

Our family chose to have the girls included because we felt like this was the placement that would prepare them the most for the real world. So we treated Special Education as a menu of services and supports rather than a place.

At the beginning of Celina's fourth grade school year, the school assigned her to a teacher who was absolutely opposed to having her, and unfortunately, no other teacher was willing to take her. This was the beginning of a very difficult and disappointing fight to have her daughter's services continue as before. The school district did not support the family's wishes, and the girls were moved to the center-based program at a different elementary school. Even though they were a part of the center based program at that point, Rosa and her husband continued to insist on an inclusive education for their daughters, which they have received ever since. However, Rosa relates tearfully, *"This was a huge defeat for me. I really believed that my kids should have graduated from that other school."* The girls had experienced several good years of being included in their neighborhood school, and many of the teachers would even stop Rosa when she was at the school to express their feeling of appreciation for having the girls in their classrooms. Thus, when the school would not back her up against this teacher, she was devastated. She recalls, *"At that point, I just threw my hands up and accepted that I would have to put my girls into the challenge program."*

Middle School. Even though her daughters were moved to the challenge program, Rosa continued to fight for her girls to be included. Unfortunately, the school insisted on sending a paraprofessional with Celina to all of her classes. Initially Rosa agreed to this one-on-one support in order to ensure that her daughter would be included in the general education environment; however, this inadvertently caused Celina to become more and more dependent on this type of support. Rosa says, *“Out of my three daughters with disabilities, Celina is the one that really could have handled more independence at school, but they never allowed her to fail.”*

Celina never had much interest in academics, but she loved school for the social aspects. Once Celina entered middle school, she was very much into being a typical teenager. She was, and still is, very interested in boys, music, and videos that are popular with other teenagers. She also doesn't like to do chores at home. Her mom describes her as a *“prima-donna”* and says that she is the *“princess of the family.”*

High School. Currently Celina is completing her senior year of high school. For the last few years she has been attending the high school Challenge Program, but she, unlike the other students in the program, participates in general education classes for the majority of her day. Accompanied by a paraprofessional, Celina goes to her classes and works on modified versions of the same activities and assignments on which her typical peers are working. The main goals for Celina participation in general education classes are for her to have the opportunity to observe and interact with her nondisabled peers, learn appropriate social skills, and learn to be more independent. Unfortunately, the paraprofessional continues to accompany Celina to her school activities despite several requests from her mother that this support be discontinued in order for her daughter to

achieve increased independence. Also, Rosa has made her wishes known that she does not want Celina participating in community outings provided by the Challenge Program.

Rosa states,

I do not want either of my daughters seen out in the community with a group of kids with disabilities being led around like a herd of cattle. Not because I don't like kids with disabilities but because I feel as if this is a very demeaning and unnatural approach to teaching these kids to function in the outside world.

Celina's Transition Program

Celina is very excited that she will have the opportunity to walk through the graduation ceremony in just a few weeks. Once students in the Challenge Program have gone through graduation they typically no longer go to the high school and are moved over into the school district's transition program for students who are 18 to 21 years of age. The transition program is designed to provide students with more significant disabilities the opportunities to explore work options; to work on life and self-help skills; to participate in recreation, leisure, and social activities; and to participate in community outings with all of the students in the transition program. While this option is the path that most students in the Challenge Program take, Rosa does not want this for Celina. She has heard from other parents that this is a very ineffective program, and that the students who attend this program do not leave with anything in place for their future.

Instead of going to the transition program, Celina will be staying at the high school one or two more years for socialization purposes and to work on skills that will help her when she transitions into a job in her family's printing business. Rosa would like for Celina to be able to attend some non-academic general education courses at the high school and then participate in some type of school job such as an office aide, library aide, teacher's aide, as well as continue to work in the school store.

Celina's Future

Celina currently lives at home with her mom, dad, and older and younger sisters who also have Down Syndrome. She has a loving family unit that is very close and supportive of one another. Even though her other siblings no longer live at home, they do not live far away and they also provide supports whenever needed. Throughout Celina's school years, her parents have been very involved in her educational experience. Rosa has been one of those parents that most teachers think of as a helicopter mom. Because she worked for so long as a parent advocate for her local state department of education, she is very knowledgeable about the school system and how it functions. Since she had two older children who went through the special education system before her two younger daughters, she is very comfortable with the system and knows what she needs to do in order to get what she wants. Unfortunately, last year she was diagnosed with cancer, and her doctors are not giving her very long to live. For the last several months, she has been undergoing treatment for her illness, and there have been no improvements in her health. Because of this, she admits,

My priorities have changed with regards to my daughters' education and the whole special education process. I am really just looking forward to the day that I will no longer have to deal with the school system and all the bureaucracy that goes along with special education

For months, she has been frantically working to put supports in place for her daughters so that they will have a secure, happy, productive adulthood even though she may not be here to see it.

Celina is currently on the waiting list to receive supported living services through the community center board. They have been told that the wait can take up to five years for these services to become available. Celina's family would like to use these services

for respite care, help with personal care/daily living activities, and community participation. The family can find someone to provide these services and the community center board will pay whoever the family finds. Rosa would be very happy if one of her family members would provide these services so her daughters would not have to have someone outside of the family come in, but she does not want to put this burden on her other children.

Celina will continue to live at home with her parents and two of her sisters. Rosa and her husband have set up a trust fund that will be financed through a large life insurance policy taken out on Rosa. This trust will help financially support their three daughters with disabilities and provide ample support for them to stay living in their family home. Rosa has also set up Medicaid to pay for Celina's medical expenses, and after Celina finishes school, the goal is that she will be employed at their family business with support from the Department of Vocational Rehabilitation. Rosa would like her daughters to be as independent as possible within their family unit but total independence has never been a goal that she has had for them. Rosa believes that independence is overrated and instead values interdependence within her family unit. She wants Celina to have a productive life through being employed. She also wants her to have an active social life, but her number one goal for all of her kids is that they are happy and that they feel good about whatever they are doing.

The Story of Koda

This is the story of Koda told by his stepmother Nina. Nina is a resourceful, courageous Native American woman who is focused on raising her children with her same traditional values. Although she did not grow up in a very stable environment, she

is dedicated to providing a loving and stable home for her husband and children. She prides herself on learning new things, finding resources in her community, and providing her children with the knowledge that will help them have a happy life.

In the Beginning

Nina, Koda's stepmom, was born in a rural, southwestern state of the United States. Her family moved around a lot when she was very young, oftentimes living in the homes of their extended family and friends. She grew up very poor, in a single parent household along with her two brothers, one biological sister, and one stepsister. Life for Nina has never been easy, but she has always been able to find a way to make it through the hard times.

Childhood Memories. Nina rarely saw her mother when she was growing up and does not have much of a relationship with her to this day. Her mother abandoned the family when she was very young, and the only memories that she has of her mother are from what she has been told by her father and her siblings. She is the youngest child in her family and recalls being left alone with her older brothers and sisters most of the time while her dad went to work. Because her family was very poor, they had to rely heavily on resources outside of their family to help provide for their basic needs. They received food stamps and commodities through their local social services program, and they would get their clothing, shoes, and household goods at "*La Segunda*" or the thrift store. Nina remembers that when she was growing up, her family lived next to a church that her father took care of for some extra income and a place to live. They were so poor that they had no running water or electricity in the house; they would have to take showers and

wash their dishes at the church and would use the church's electricity because they could not afford it on their own.

School Memories. School was not something that was valued in Nina's family and was seen as a "*glorified babysitter*." Nina struggled in school due to her home life, ultimately having to deal with issues of abandonment and neglect she faced by being left alone without adult supervision most of the time. Nina first entered the juvenile justice system when she was in the 5th grade. She was in and out of this system until she turned 18 years old. During this time she was able to get her GED. She went on to graduate from community college with an associate's degree in respiratory therapy and received her EMT license. Even though education was not something valued in her family when she was growing up, she knew that it was the only way that she would be able to have a different life. She wanted more for her children. She wanted to give them everything she did not have as a child.

Becoming a Parent. Nina met Koda's dad at a party put on by some of their mutual friends. They were instantly attracted to each other and fell in love very quickly. Although they have never been officially married, Nina and her husband have been together for over two years now, and they consider themselves husband and wife. Nina and her husband have a large blended family that includes her sister's three children, her husband's three children, her child from a previous relationship, and one child they had together. Koda is the oldest biological child of her husband's children. He was in early adolescence when Nina and her husband got together. Nina feels like there have been many positive changes in all of their children's lives because of their union.

Nina and her husband feel like they have many old fashioned family values that they would like to pass on to their children. They believe that the men and the women in the family have very different roles. For example, the man is responsible for the family finances, making decisions around the house, and working to support the family while the woman's roles focus more on cooking, cleaning the house, and taking care of the children. Koda's dad works as the manager in the meat department at the local grocery store, which is the only income for the family. Nina is responsible for raising the children and taking care of the home. Although, they do value independence within the family, their children are not allowed to participate in decision-making. However, because they have several young children at home, the older children, including Koda, are expected to take some of the responsibilities around the house. Nina says that they tend to be harder on Koda because he is a boy and because he does not have many of the skills needed to take on some of these responsibilities. She stated that it is difficult to know how far to push him because of his delays. She feels like Koda is too dependent on them and would like to see him be more independent within the family unit.

The School Years

When Koda was a very young child he lived with his dad, biological mom, and two younger sisters. His biological mother was emotionally and physically abusive to him and his sisters. His dad was an alcoholic who was basically absent during this time of Koda's life. Koda was seriously affected by the abuse and neglect that he experienced while he was very young. Because of this, he has severe delays in his physical development, cognitive abilities, school achievement, social skills, interpersonal relationships, and emotional development. His dad eventually divorced Koda's mom and

took the children to live with him. Unfortunately, this situation was not much better for the children since their dad had to work full-time to provide for his children combined with the fact that he continued to drink excessively on a regular basis.

Elementary School. Koda's emotional and cognitive issues caused him to have a very difficult time once he entered the school system. He struggled both academically and socially in school. Koda was a very withdrawn child who lacked curiosity, was not able to relate to other people, and seemed uninterested in his surroundings. From the beginning of kindergarten, Koda received special education services. Unfortunately, neither his father nor biological mother were ever really part of this process. Koda received his educational services in a center-based, self-contained program for students with moderate to severe disabilities at his local neighborhood elementary school. His program consisted of learning functional academic, self-help skills, communication and basic language skills, and behavioral modifications and supports. Although school staff tried their best to provide Koda with a quality education, the effects of his traumatic early childhood abuse and neglect made it very difficult for him to make much academic progress.

Middle School. Behavior has always been a major challenge for Koda in school and at home. As Koda entered middle school, his behavior remained a problem. His behaviors included being hyperactive, having a short attention span, displaying chronic anxiety, appearing depressed, displaying flat affect and lack of emotions, and withdrawing from enjoyable activities. He could lose his temper very easily, have aggressive outbursts, and would express himself inappropriately several times a day by shouting swear words and vulgar language.

Koda continued to receive his educational services within a self-contained special education classroom with emotional and behavioral supports being the main focus of his program. School staff felt that because of these services, Koda's behaviors began to improve, and he was able to make some academic progress. However, he still needed improvement in social skills and his ability to relate to other people. Because of this they tried to include him more within the general education environment, mainly for non-academic classes such as P.E. and Art.

High School. When Nina first became involved in Koda's educational services she was very concerned that he was not getting the help he needed through the school system. She took it upon herself to set up some services outside of school to get Koda some extra help. An example of the services she set up for him was a counselor through the mental health department. She also enrolled him in a transition program through mental health, which worked on different skills that he would need when he graduated from high school. This program also provided him with a mentor and gave him an opportunity to go on social outings. He also participated in a wilderness program where they addressed social skills and working with other people towards a common goal. Although Nina felt like these services were beneficial for Koda, they were only in place for a short period of time.

Nina has also taken on the role of communicating with the school, attending Koda's IEP meetings, and making arrangements for any of his post-school service needs. Behavior has continued to be a challenge for Koda, but this has improved over the last few years at school. Despite these behaviors, Koda now seems to get along well with many students around the school and seems to make friends just about anywhere,

according to his teachers. The school has also reported that he is very helpful around the classroom and is reliable when performing tasks that have been explained thoroughly to him.

However, Nina describes him as a much different child at home. She describes him as very needy and dependent. She says that he is not able to socialize well except with little children who are functioning on his same cognitive level.

His current special education program has focused on spelling and sight word instruction, writing skills, decision making and problem solving skills, controlling his temper, technology skills, math skills focusing on money, and expressing his wants and needs in appropriate ways. He has goals and objectives on his ITP that focus on all of these areas. He also has participated in P.E., Art, Computer, and Woodshop during his years in high school. Nina has been upset about Koda being in Woodshop because she said that he gets loaded up on soda and candy, plays on the Internet the whole time, and just goes around and helps other students with their projects instead of actually having to do his own project. His parents asked the school to take him out of this class, but he has continued to take it every semester. She feels like the school has totally disregarded their wishes on this issue. Nina also believes the services that Koda has received in school have not prepared him to become a successful adult. She feels like the school has not focused enough on skills that he will need once he leaves the school system. She believes the school system has reinforced his learned helplessness.

Koda's Transition Program

Koda is 18 years old and is about to finish his senior year. Next month he will be graduating from high school and moving into the adult service arena. As part of his

transition class, Koda participates in a community outing once a week to the local grocery store to purchase something to eat and practice money skills. Nina is concerned because the school tells them that he has been working on telling time and counting money, but when she tries to have him do the same things at home he is not able to perform these tasks. Because of this, Nina asked his special education teacher to send some work home that he would typically do at school so that they could help him with it. The teacher did this for about two or three months, and then it just stopped because it was an extra responsibility. She said that every time she has gone to the school, Koda is either just sitting there, playing on the computer, or looking at a magazine. She does not feel like he is doing anything educational and that is why she gets so upset with the school.

Koda's Future

Koda is eligible to receive services through the school district until he turns 21 years old; however, his parents have decided that he should graduate from high school this year since he is now 18 years old. Although this has been a difficult decision, they feel like this is the best decision for him since he has gotten into trouble at school for fighting. Now that he is 18 and considered an adult, they fear that this type of behavior could lead to him getting in trouble with the law. Currently, Koda is enrolled for day services through the community center board. He will participate in employment activities and social outings four days a week for half a day. He has been placed on a waiting list for residential services in a group home or some other type of supported living environment through the community center board, and has been linked with the Department of Vocational Rehabilitation to be evaluated for employment services. Although the school district has documented that it has made connections with these

adult agencies for Koda, Nina does not feel that the school has connected them with any outside services. She reports that she is the one who searched for services that would be appropriate for Koda once he graduates from school. Nina shared, *“I feel like I can help my son be more successful in adulthood than the school can.”* Sadly, she states, *“I have given up on the school doing anything to help my son achieve success.”*

Koda’s family has several dreams for his future life. Their ultimate goal for Koda is that he is an independent, successful adult who is able to live and work in the community as well as get married and have a family of his own some day. They would like for him to be more independent and be able to live on his own. However, they feel like this will never be something that he is going to be able to accomplish since he currently needs so much supervision. They would also like him to attend some type of post-secondary education, like a trade school, but feel that he would not be successful due to his level of cognition and inappropriate behaviors. Employment is another dream that they have for Koda, but they can never see him being employed outside of a supported work environment. They feel like Koda is going to end up living a life of isolation because he currently has no social life and no friends. Nina says, *“It is very hard just to know that this child, who I love so dearly, will never be able to be who he wants to be.”*

Summary

This chapter has introduced each of the five families that participated in this study, using stories developed primarily from interviews but also from reviews of the IEP documents, observations while in the families’ homes, and demographic sheets filled out by the participants. Each story contains the descriptions of significant experiences and events in these families’ lives that have influenced their perspectives of how their

children with significant disabilities are transitioning out of the school system. Based on these unique experiences and events, each family has developed particular perspectives and expectations of this process as their child moves out of the predictability of the public school into the adult world. These stories provide a basis for understanding the findings that will be presented in the next chapter.

Chapter V shows the data analysis and discusses the findings from this study in relation to the six components of grounded theory. These components represent the data analysis and the theoretical structure that has emerged from the stories of these culturally diverse families.

CHAPTER V

FINDINGS

This chapter presents the results of a qualitative assessment of culturally and linguistically diverse parental perspectives on the transition services being provided to their children with significant disabilities. A theoretical model is presented to provide an organization of the participants' responses in relation to the primary research question being addressed in this study:

What are the experiences and perspectives of parents who are culturally and linguistically diverse on the transition services being provided to their children with significant disabilities?

Data collected to answer this research question included a series of three separate in-depth, semi-structured interviews with family members, observations while in the families' homes, demographic sheets filled out by the participants, and IEP document reviews. Supporting the process of answering this question were four guiding questions.

These were:

- Q1 What are the expectations of parents who are culturally and linguistically diverse regarding the post-school life of their children with significant disabilities?
- Q2 What stories do parents who are culturally and linguistically diverse tell that illustrate their feelings and experiences with the transition process of their children with significant disabilities?
- Q3 Are there concerns or barriers facing parents who are culturally and linguistically diverse regarding their involvement in the transition process of their children with significant disabilities?

- Q4 In relation to program documentation (e.g., IEP/ITP), are there discrepancies between parental expectations and parental descriptions of their children's service needs when these are compared with the expectations and the services provided by schools?

These questions were considered in the development of the interview and in the way the interviews were conducted. These questions were also referred to during model construction to ensure the fullest and richest picture possible of the lives of these families and the transition process.

This chapter reports an analysis of these interviews, using grounded theory methodology. Based on this methodology, the data were organized into six components representative of the paradigm model of the grounded theory process (Creswell, 1998; Strauss & Corbin, 1990). These components are: (a) causal conditions; (b) phenomenon; (c) intervening conditions; (d) context; (e) action/interaction; and (f) consequences resulting from the action/interaction. Causal conditions are the conditions that "caused" the central phenomenon to occur. The phenomenon is the central idea or category that emerged from the data that connects all other components of the theoretical model. Intervening conditions are broader conditions within which the action/interaction occurs. These conditions existed regardless of the causal conditions, yet served to alter those causal conditions in either a positive or a negative way. These conditions might also influence the action/interaction in response to the central phenomenon. The context is the particular sets of conditions that relate to the phenomenon and within which the action/interaction occurs. The action/interaction is the specific strategies that occur as a result of the central phenomenon. Finally, consequences are the outcomes of strategies taken by participants in the study. These components symbolize a theoretical

reconstruction of the data that serve as a basis for a broader paradigm of experiences and perceptions of the transition process experienced by the parents in this study.

The theory components that were derived from these data are shown in Figure 1. The data used to compose these six components are presented and analyzed in subsequent sections. Each section describes a particular component of the theory model. A brief summary is then provided at the end of this chapter.

To fully understand the model, the concept of *phenomenon* needs additional explanation. Again, phenomenon is the occurrence that is central to the theoretical model and connects all other components of the model together. There are specific variables that cause the phenomenon to develop. These variables can be influenced by other external variables which in turn either support or constrain the phenomenon. Because of this, certain actions/interactions occur in response to the phenomenon, resulting in specific outcomes.

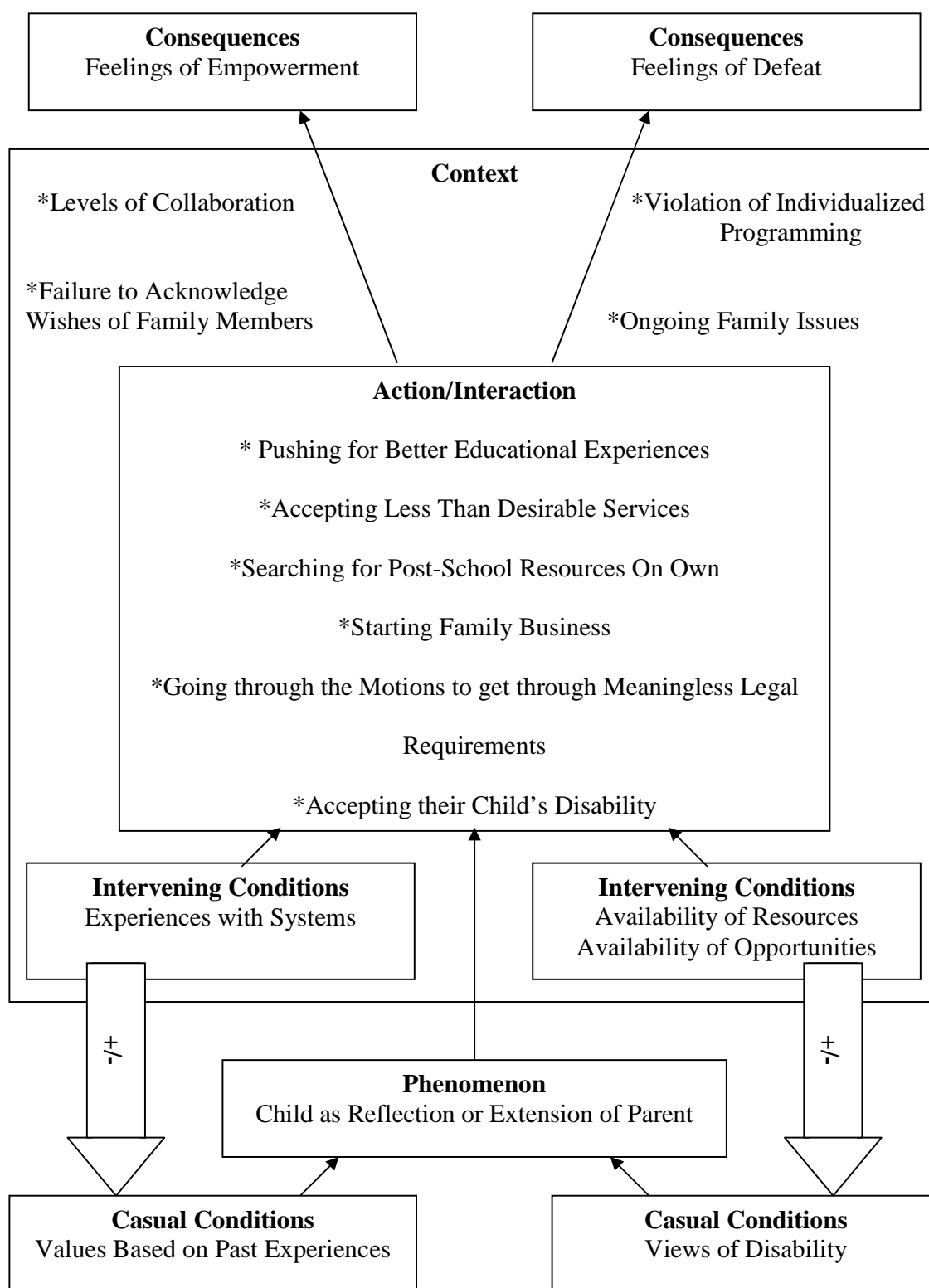


Figure 1. *Theoretical Model of Culturally Diverse Parental Perspectives of Transition Services for Children with Significant Disabilities*

Causal Conditions

Causal conditions have been defined as “events, incidents, [or] happenings that lead to the occurrence or development of a phenomenon” (Strauss & Corbin, 1990, p. 96). The phenomenon, directly influenced by the causal conditions, would not exist in the same way without the presence of all or at least most of the causal conditions. In fact, it is rare that a single causal condition would construct a phenomenon.

A variety of different events can be considered causal conditions, for example, something someone says, specific behavior of a person, and/or something a person does. “Causal conditions, or antecedent conditions as they are sometimes called, are often pointed to in the data by terms such as: ‘when,’ ‘while,’ ‘since,’ ‘because,’ ‘due to,’ ‘on account of’” (Strauss & Corbin, 1990, p. 101). Based on collected data, two main causal conditions emerged, which ultimately led to the development of the central phenomenon in the participants, as shown in Figure 1. These conditions were: values based on past experiences and views of disability.

Values Based on Past Experiences

Values based on past experiences were those conditions that existed, or events that took place, in the participants’ lives that led to the development of their current personal value and belief systems. These conditions had a significant influence on the expectations participants had for their children, including their child with a significant disability. These past experiences create the foundation of how each of these families defined a successful adult life for their children. Participants discussed past experiences or expectations from their childhood that lead to the development of what they currently valued or believed to be important in helping their children with disabilities become

successful adults. These values and beliefs have been organized into the following categories: value of education, value of employment, and value of independence.

Value of Education. Participants in the study described at least one condition that influenced the way they viewed and valued education. For all participants, these particular experiences or family expectations were described as something taking place during childhood or family expectations that had direct bearing on the expectations for their children's education or the services their children were receiving through the school system.

Several participants in this study indicated that education was a primary family value. Some of these families recognized that education was a way to improve economic circumstances. Regardless of their views of education, all participants had some post-secondary education experience or held a degree from an institution of higher education. One participant held a graduate degree, another participant held a bachelor's degree, one had an associate's degree, one had received a certificate from a community college training program, and one had a degree from an institution of higher education outside of the United States. Those expectations were then transferred to their children with disabilities, and to the school system. These strong educational values were indicated by quotes such as: *"One thing I know is that my father, he always pushed me when it came to school"* (Maria); *"I explain to my children how your life can change . . . from having a degree and not having a degree. Not only money. Money of course is something that will help you but it is more important for personal goals"* (Karina).

Some families indicated more negative views of education based on previous experiences. Latoya, Jamar's mom, referenced a turbulent view of education based on segregation. This view was transferred to the expectations of education for her son:

As an African-American mother I'm thinking nobody is going to segregate my kid from the rest of the community. I grew up with it; fought to keep . . . from being segregated and here we are now . . . we can still segregate groups of people because of a perceived deficit. You are not going to send [my son] to a different school because of who he is. So I did a lot of fighting for inclusion.

Rosa, Celina's mom, grew up in a family that did not encourage their children to go to college even though they wanted her to get a good education, evident through their sacrifice to send her to a private catholic school even though they did not have the financial means:

In the Hispanic culture there is a tendency to fear higher education because it has the tendency to take your kids away from you. Especially if they go off to Timbuktu they don't come back. So I think there's always been a little bit of that fear and so back then it wasn't as encouraged as it is now. I would die if my kids moved away. I couldn't deal with that. I would hate it. So there's probably an unconscious encouragement to keep them close and I have managed to do that.

Nina, Koda's mom, spent the majority of her education in the juvenile justice system. However, based on past experiences and watching the challenges that her family had to go through during her childhood, education became something that she later felt was very important in making her life better.

Value of Employment. Participants in the study also described experiences they had or expectations placed on them by family members that had an impact on the way they viewed and valued employment or work experiences. These events or expectations had a direct bearing on the expectations they held for their own children to participate in

work activities while in school as well as becoming employed once they exited the school system.

Some participants in this study indicated that employment or work experiences were an important value in their family. A few participants were even expected to work while still living in the family home in order to help support the family. This strong value of employment was indicated by quotes such as: *“Mom and dad expected that we would share in the finances of the household as long as we lived there . . . so we were all working by the time we were sixteen”* (Rosa); *“I actually started working when I was 13 . . . so I have a lot of work experience”* (Maria).

This work ethic was something participants tried to instill in their children. Because of this value of employment one family even started their own family business so that their children with disabilities would be able to find meaningful employment. Rosa, Celina’s mom, shared:

Our two older kids with disabilities were leaving the school system, [and] didn’t have anything to do and I had kept telling [my husband], “You know, you always said printing would be a good place [for our kids to work] so let’s do it.” So we now own and operate [our own printing business].

Although most participants saw value in having a work ethic, some of the other participants did not see employment or work experiences as a primary family value. These families indicated that they felt there was more to life than just work experiences. These views were expressed through the following quotes: *“I would like to see [him] doing something that would engage his mind . . . it has to go beyond more than what he can do but something he likes to do”* (Latoya); *“I think also there’s a life outside of work so I want more than just work for him”* (Nina).

Value of Independence. Independence was another value that parents who participated in this study discussed with regard to their expectations of the post-school lives of their children. All participants discussed past experiences that led to the development of how they currently view and value independence. Along with the idea of independence, participants also discussed elements of independence or interdependence that apply to their family structure. These included extended family involvement, outside agency involvement, and decision making within the family.

Because of her own independence, Latoya has always wanted her children to have this same sense of independence. She described her hopes for them as they move toward graduation in a few years, *“My goal, and it’s been the same for both [my] kids, is to spread your wings and be able to live independently.”* Nina also expresses her hopes for her son, Koda’s future. When asked what goals she has for your son’s future she shared, *“Just independence. I really, really wish for my son, that he could do things on his own. He could have his own place and have his own freedom.”* On the other hand, Rosa, Celina’s mom, who grow up in a family that was very close to one another, feels like we put to much emphasis on independence. She stated, *“I’d be a liar if I said I encouraged total independence and that’s partly because I’m a mother. I truly believe that independence is too overrated. I think it’s really interdependence that is important.”*

Despite whether these parents valued independence or interdependence, having a child with a significant disability most likely will require these families to rely on others, outside of their immediate family, for support at some point in time. Whether this support comes from extended family members or community agencies, total independence for

these families and their children with significant disabilities is most likely not an option for the future.

Extended Family Involvement. One element of independence discussed by participants was extended family involvement. Some participants in this study had extended family members who provided a large amount of support to them, and others had very little involvement from extended family. If the participants grew up in a family that was close and had extended family support during childhood, they had continued extended family support once they started their own family. Two of the families had assistance with respite or child care for their children with significant disabilities; another family received financial support from their extended family.

Maria, Esperanza's mom, recalled:

[My mom and dad] have supported me. They have babysat [Esperanza] since she was a baby for me when I went back to work. They have supported me financially when I was having a difficult time. They have supported me in every way.

However some families did not have extended family involvement. Those families had either moved away from family members, their extended family lacked financial resources to provide support, or their extended family members did not want to provide support, sharing,

Whose care is he going to be under? I've heard from my in-laws, you know, who are like, "have you made out your will yet? Because you know we can't take care of him." So it's a challenge. Even our family is really reluctant to even offer support because they don't want to be "The Ones" that have to take care of this child, the one child out of all the grandchildren that has special needs (Latoya).

Without support from extended family and friends many families with children who have significant disabilities are forced to look for support outside the family circle, which can be stressful and can push them outside their comfort zone. Along with not having

extended family support, Latoya, Jamar's mom, also had concerns about asking friends to help:

I am kind of reluctant sometimes to ask for help from my friends. I can watch their kids and it's no problem because their kids don't have disabilities. For them to watch my kids, you know, I don't want to come to their house and find out a window's been broken, you know, my son can be such a handful. I don't feel like I can ask them for help.

Outside Agency Involvement. Another element of independence discussed by participants with regard to their children with significant disabilities was to seek support from agencies. Based on their past experiences, some participants were more comfortable relying on outside agency support than others. Some participants who grew up in low income families had more extensive involvement with outside agencies in their childhood. These participants expressed distrust of outside agencies through the following quotes: *"I remember growing up on welfare. They were so hard on my dad and I've seen how much it bothered my dad. I would say that I don't trust agencies"* (Nina); *"Systems were to be avoided. [My family] didn't want to get into the social services system; you didn't want to have to rely on welfare. My mom was very adamant about staying off welfare"* (Latoya).

Despite how they felt, all participants in this study were receiving outside agency support in some way during the time of the study. Rosa, Celina's mom, preferred to rely on family members for support but admitted her reliance on agency involvement had increased over the past year due to her own ongoing medical issues. Latoya admitted to currently using outside agency support, but in some ways felt like there were no other options available for support. She stated:

I understand that these agencies were put in place to help and assist. What I distrust about them is that it is suddenly their judgment is in place of mine. So

what I used to be able to do and the decisions I used to be able to make for my own child, suddenly, I've got someone saying, "Well, the agency does this and therefore your decision is going to be this in order to be consistent with the agency." There's not a lot of flexibility there. I think a part of it, too, is I see the agencies at work and the decisions that they make are not always because of the child's needs but because of their resources. So I am using the system. I have seen that it helps in many ways. It is very helpful because I can get respite care so that my husband and I can go out once in awhile or go on a trip but it's not easy. It is not easy.

Decision Making. The final element of independence discussed by participants in this study was decision making. This consisted of how each family dealt with and viewed the process of decision making for their whole family as well as the roles of their children within that decision making process. In addition, they discussed their expectations when it came to their children being involved in decision making for their own day-to-day lives as well as making decisions for their future.

Some participants felt it was important to include their children in making important family decisions. These families also felt like it was important for their children to make decisions for their own lives. These views were evident through the following quotes: *"At a very young age [children] made their own decisions about everything. You don't control them"* (Maria); *"It's really important that they have a say in things that are going to affect them. I want them to go out into the world and make their own decisions and have a chance to think about it"* (Rosa).

Other participants did not feel it was appropriate for their children to be included in the decision making process for the family. One participant in particular admitted there are some family decisions that do not warrant input from their children. She stated, *"We go through stressful times quite frequently. I don't want to involve the kids in adult challenges. I do have the last word. I will admit it"* (Latoya).

Whether or not these parents included their children in family decision making processes and/or decision making for their own individual lives, they had, to some degree, conflicting expectations for their child with a significant disability. This applied not only to decision making but to their values of education, employment, and overall independence. In the next section, the second causal condition, views of disability, is discussed as well as how parents' values based on their past experiences might be influenced by their views of disability and vice versa.

Views of Disability

Views of disability were the participants' perceptions of people with disabilities. That is, how they defined someone with a disability as a person, what words they used to describe them, what they thought they were capable of doing in the future, and the expectations they held for them based on their own cultural values and belief systems. These conditions had a major influence on expectations these parents had for their children with significant disabilities. Participants discussed events and interactions they had with people who had disabilities in the past, learning opportunities and training they were involved in that focused on people with disabilities, and beliefs and views about people with disabilities that were installed in them from family members and friends as well as societal norms from their childhood. These experiences had an influence on how they viewed disability in general as well as how they viewed their own child's disability. Furthermore, they influenced how they viewed the services their child was receiving in school and parental expectations of those services. Participants described events in their past that influenced their views of what having a disability means and this influenced how they defined a successful life for their children with significant disabilities. These

experiences and events were critical to how participants viewed the future for their children, thus creating the foundation of how families defined a successful adult life for their children. The primary influences impacting the participants' views of disability were, exposure to people with disabilities and educational experiences about people with disabilities. These experiences or events had a direct impact on the expectations that these parents had for their children with significant disabilities and often created conflicting expectations.

Exposure to Disability. Exposure to people with disabilities was one of the primary influences impacting participants' views of disability. Exposure can be defined as being around people with disabilities, interacting with them, or providing them support. It can also mean seeing people with disabilities out in the community, being influenced by others' views of people with disabilities, or being aware of how people with disabilities have been treated in the past.

Two participants had large amounts of exposure to people with disabilities either through growing up with a family member who had a disability or through their place of employment. This exposure helped them to see disability as just a normal part of life. These positive views of disability were expressed through the following quotes: *"As a result of my work, I came in to contact with all kinds of people with disabilities so disability doesn't faze me"* (Rosa); *"My dad was hurt in the service so he always had a disability. I knew that my dad had a hard time walking and he ended up in a wheelchair but that was normal"* (Maria); *"My dad was this very macho man. A caretaker who did everything, and he eventually got to be total care. So anybody who thinks that they're not going to be associated with disability in some way is fooling themselves"* (Rosa).

Another participant was influenced by the way that people with disabilities have been treated in the past. Latoya described how her knowledge of the treatment of children with autism affected how she dealt with her own son being diagnosed with autism. She recalled:

When I got the diagnosis, I'm going home and I'm stretching back in my memory thinking okay, autism. What do I know about autism? Have I ever seen any autism? And my only recollection of what happens to people with autism is they got institutionalized. And so I was crying my eyes out one day and my husband came up and he said, "It is going to be alright." And I'm like, "No. They institutionalize kids with autism."

This once common treatment practice of individuals with significant disabilities had a huge impact on how Latoya viewed disability in general as well as how it impacted her expectations for her son and for the services he received through the school system.

Along with being around people with disabilities, providing support to them, and being aware of how they have been treated in the past, religious beliefs were also a factor influencing one participant's views of disability. Karina, C  zar's mom, described the feelings her family had when they first realized that their son had a severe disability, sharing:

In the beginning it was kind of shocking. I mean in the beginning was a lot of "whys." The church says that we have been selected to raise this special kid. It was kind of like yeah, maybe they are right.

The comfort that they received from this knowledge gave them the ability to accept and deal with their son's disability. Furthermore, it had an impact on how they viewed their son's disability and the expectations they held for their son. Karina shared, *"We know we can't expect too many things from him. So right now it is kind of just enjoy what we have, you know, and don't be worried for what he can't do or can't change."*

Disability Training and Education. Another major factor influencing participant views of disability was their opportunity to participate in training or educational experiences focusing on people with disabilities. Several parents in this study discussed their choice to participate in educational opportunities or training focusing on some component of disability. These events had a major influence on how participants viewed disability, thus influencing how they viewed their own child's disability and the services they were receiving through the school system.

Two participants went back to school to earn a degree related to special education. Both participants felt like they could use their education to make changes in the implementation of special education services. These views were shared through the following quotes: *"I used it to go back to school and educate myself because I know that I want to help kids like [my daughter] because I know [she] is not the only kid like that in this world"* (Maria); *"I have been thinking what's the best way to create some change because when I see how special education is being implemented versus the law and intent of the law, it is two very different things"* (Latoya).

Rosa, Celina's mom, also described training she attended through her employment as a family advocate that had a huge impact on her view of disability and eventually her expectations for services her children with disabilities received through from the school district. She recalled:

I took part in a program here that was called Partners in Leadership. And as part of your participation in that, it was a like a seven month training project and you would go to a hotel with a group of other people who had been identified parents and adults with disabilities. That was a big "ah ha" for me because it was my first time listening to what people with disabilities had to say about themselves as adults. So it helped me to really say well if that is what they want for themselves that is what I should want for my kids. They brought in some dynamite speakers from around the country who were very state of the art about

inclusion. And that was the big switch for me. Now that's when I became an inclusion purist.

Again, because of these educational and training opportunities the views of these parents were influenced. More importantly, because of these opportunities the views of the services being provided to their children with significant disabilities were influenced. It is safe to say that because of these educational experiences these parents were more active participants in the education and transition planning process for their children as opposed to parents in this study that did not have opportunities to participate in educational or training programs.

Conflicting Expectations at the Interpersonal Level. It was discussed in the first section of this chapter how “values based on past experiences” is one of the two casual conditions. It was also described how past experiences and events had a significant influence on the expectations the participants had for their children and that these past experiences created the foundation of how the families defined a successful adult life for their children. For example, some parents grew up in a family that valued education, that pushed them to achieve in school, and that strongly encouraged them to attend some type of post-secondary education. Thus, these parents developed their own value of education based on these experiences and expectations and wanted these same experiences and expectations for their children.

Whether or not parents valued education, employment, or independence based on their past experiences, to some degree, conflicting values and expectations emerged with the birth and subsequent care of a child who had a significant disability. For example, if a participant grew up in a home that valued education and they themselves valued education, it was highly likely that they had high expectations for their children to

achieve educationally and thus, wanted them to attend some type of post-secondary education. However, given a child with a significant disability, they may or may not have these same expectations for that child. Many times these conflicts in expectations were caused by intervening conditions, experiences with systems and availability of resources and opportunities, which will be discussed in greater detail later in this chapter. These intervening conditions had either a positive or negative impact on the way participants constructed their expectations for their child with a disability, the values and beliefs they had for their child's future adult life, and the expectations they had for their children's services within the school system.

Conflicting Value of Education. As stated previously, participants described at least one life experience or expectation placed on them in their childhood that influenced their value of education. These particular experiences or family expectations had a direct bearing on expectations they held for their own child's education and the way they viewed services their child was receiving through the school system. Some participants grew up in families where education was highly valued and in turn, they also had a high value of education and high expectations for their children's education including an expectation for them to attend post-secondary education. However, attending post-secondary education was not an expectation for their children with significant disabilities.

On the other hand, some participants grew up in families where education was not highly valued. For example, one participant grew up in a family that did not expect or encourage their children to go to college and, although she has had high expectations for her children's educational services in the public school, her goal has never been to prepare them for post-secondary education. However, based on participants' past

experiences and educational opportunities their expectations for their children varied. For example, one participant grew up in a family where education was not highly valued, and despite the fact she did not attend post-secondary education until later in life, she did place high value on educational opportunities. One of her goals for both of her children, including her son with autism, was to attend post-secondary education so that they would have the opportunity to experience the “*college life*.” Another participant grew up in a family that did not value education, but based on her past experiences and watching the challenges her family went through, educating herself became something she later felt was very important in making her life better. However, she did not have an expectation for her son to go to college because of his disabilities.

Conflicting Value of Employment. As previously stated, participants described experiences they had or expectations placed on them by family members that had an impact on the way they viewed and valued employment or work experiences. These events or expectations had direct bearing on expectations they held for their own children to participate in work activities while in school as well as becoming employed once they left the school system.

Some participants in the study grew up in a family with a strong work ethic and tried to establish this same value of employment with their own children. One family even went as far as to start their own family business so that their children would have somewhere to find meaningful employment. However, because of their daughter’s significant disability, they were not sure if she would be employable, stating:

At this point, I said to [my husband], “do what you can, honey. Do what you can to get her productive, to get her at the shop. Doing something meaningful and if it doesn’t work she may need a day program.” I don’t like day programs. I don’t but I also know that some people need them (Rosa).

Maria, Esperanza's mom, also expressed how important work experiences were for her family and the fact that she believed with proper supports her daughter would be able to participate in work activities. However, this is not really something she has been preparing her daughter to do. She admits that she only takes her daughter to recreation and leisure activities, such as bowling and swimming, with the school transition program, sharing, "[We go] when they go bowling or they go somewhere where I know she would be excited about doing it." Latoya, Jamar's mom, also wants him to have a job when he gets out of school. However, she wants it to be something enjoyable and engaging to him not just working to work. She stated:

Once he gets started he just loves to work. That is what everybody at the school keeps telling me, "Oh he loves this job." But they have him doing really repetitive tasks. So for him, you know, I don't know if that is what he wants to do or he just does it because it's something that, you know, he knows what comes next.

Conflicting Value of Independence. As previously mentioned, the value of independence was discussed with regards to expectations these parents had for their children. All participants discussed past experiences in their own lives or expectations placed on them during childhood that led to the development of how they currently view and value independence.

Because of childhood experiences Latoya developed a sense of independence. This sense of independence was something she wanted to instill in her own children. However, she admits to having different expectations for Jamar than she has for his brother. She shared:

I don't want [Jamar] to be dependent on us, but it's hard to let go and say, "Okay you can do that on your own." So I do have some similar expectations. You are going to grow up and you are going to leave home and live independently or as independently as you possibly can. My expectations for [Jamar] can be

lower than [his brother] but my expectations for [both of] them are going forward.

Nina also expressed hopes of independence for Koda's future. Although, independence is something she wants for him, she doesn't believe that it is possible. She stated, *"He'll never be able to be on his own. Because I mean, cognitively, he doesn't think through things so he needs constant supervision. He can't be thrown into an apartment by himself."* Rosa, Celina's mom, as previously stated, grew up in a very close knit family and feels like our society puts too much of an emphasis on being independent. However, she does admit she would like for Celina to be as independent as possible and feels like there needs to be a balance between independence and interdependence. She explained:

As far as her being as independent as she can be, I think we are on the same wavelength. I think she should love to have as much independence as possible and certainly we would like to support her in that but our recognition of what she is capable, in terms of independence, may be different from what her idea is. All I can say is that if I'm not around I hope that people will allow her as much independence as she can handle but not force it on her to a point that she is not going to succeed.

Although all participants said they wanted their children with significant disabilities to be independent, for most the independence they described included three main concepts: (a) independence within the family unit; (b) independent living outside the family home; and (c) safe choices. Independence within the family unit was described by participants as performing things such as taking care of themselves, being able to pick out their own clothes, and taking their own showers. Nina, Koda's mom, shared, *"We do encourage independence. We want them to be able to cook for themselves. We want them to be able to attend to themselves because we have little ones that we have to attend to."* Although Rosa, Celina's mom, values interdependence over

independence, she feels her daughters do need to learn independence within their family unit. She stated:

I think that we have a good level of interdependence but I am beginning to see that with [Celina and Marcella] I should have pushed a little bit harder on the independence in terms of taking their own shower, cleaning their room, help after dinner, and we're working on it. My next goal here is going to be working on getting them to fold their clothes and then take them upstairs and they're capable of it. They are just my last two.

Latoya, Jamar's mom, who places a high degree of importance on independence also described independence for her son in terms of independence within the family unit. She explained:

The biggest example of independence you will see in my household at any given moment is around food. [Jamar] will make a potato and cut himself a bagel or cook himself a can of soup. And, you know, it's a matter of clean up and everybody has chores.

After transitioning into adulthood, most times families with children who have significant disabilities face a decision of whether or not their son or daughter should move out of the family home. This decision can be difficult for many families to make, especially if they are unsure of available supports for independent living. Some participants did not see their son/daughter ever moving out of the family home. This was not an expectation they had for their child. For example, Karina, César's mom, did not want her son to live outside the family home. She stated, *"I don't want him to leave home. At least not right now. He is so used to us and we understand. If he leaves I don't know if he is going to be treated fine or not."* Likewise, Maria did not have the expectations for Esperanza to live outside the family home either. She shared, *"If [Esperanza] wasn't living here I would be devastated. I can't imagine her being gone."*

Rosa, Celina's mom, also did not want any of her daughters with disabilities to move out of the family home. She shared:

I have no dreams of [my girls] living on their own, in their own apartment. I have seen too many adults with disabilities out there, living in their own apartment, living sad lives totally segregated from the community. My hope is that they never have to move but that somebody else moves in or out.

On the other hand, Latoya did have an expectation for her son, Jamar, to move out, but feels like it might not be right out of high school. She explained:

I don't have a dream of him owning his own house, but I do have visions of him living in his own apartment. I do see if somebody is not living with him, somebody needs to be checking on him fairly regularly. I would love for it to happen when he is eighteen but I know that is not going to happen. I'm thinking, you know, given that he's maturing at a rate that is much lower than his peers, I think probably maybe mid-twenties he might be ready to do that. I'd love to see it earlier. It is going to take a lot more effort to have that happen but I'd be happy if he were doing that in his mid-twenties.

Nina, Koda's mom, would like her son to move out of the family home into a group home right out of high school, but it appeared to be more of a respite care issue because of the amount of younger children in their family, the short lived relationship between Nina and Koda, as well as the limited availability of services in their community. She stated:

We're on the waiting list for the group home. I would like for him to get his independence, you know, have to cook for himself and things like that. There was one opening in the group home and we did voice our interest in that position in the group home. Being in the group home would be really good because he would stay during the week and I could go pick him up on the weekend if I so choose. That would give us a little bit of a break from him and then we can handle the fidgeting and the being nosey and making comments and things like that. We would be a lot more capable of dealing with those if we didn't have him doing them, seven days a week, twenty-four hours a day. So I think if we had a little bit more services to keep him busy to kind of give us a break. I guess it would be a lot easier for him as well as for us.

Along with independence each participant discussed the process of decision making within their family and the role of their children when it comes to this process. Most participants did want their children with significant disabilities to be included in making decisions for their own lives. However, the decisions most of them allowed their children to make were described as “safe choices” or decisions that would not have negative consequences or a huge impact on their life or on the lives of their family members.

Maria described how she allows Esperanza to make decisions for her own life.

She explained:

I'll ask what she wants to eat or I'll ask her what she wants to wear. If we go somewhere and she doesn't want to go I tell her, "It is up to you. If you don't want to get down, don't get down." I mean it is kind of like simple stuff with [Esperanza] cause she will tell you when she doesn't want to do something. I give her safe choices

Rosa, Celina's mom, also described how she feels about allowing her daughter to make decisions about her own life. She stated:

I think someone is going to have to make eighty-five percent of her decisions. It is more preferences that she's vocal about although preferences can determine decision making but in my mind she's got more preferences than she really does the ability to make serious decisions. Simple decisions like, "Do you want to go with me to get [your sister] or do you want to stay home?" Those little decisions, you know, day to day decisions, she can make and she is very good at making them. Decisions about where you want to live when you grow up, she will probably tell you with [her older sister], my daughter that moved out. They all want to move in with her in her apartment, boyfriend, dog. They all want to so you know important life decisions I think she is going to need help with. But day to day preferential type of decisions she will be able to make those. "Do you want to go to Applebee's or Ruby Tuesdays?" She can make those, you know, those kinds of decision she can make them. But decisions about how the rest of her life, we make them.

Likewise, Latoya, Jamar's mom, who very much wants her son to live independently, described how her son makes decision in his life. She admitted that she feels she has not prepared him adequately to make his own life decisions. She shared:

I see him making decisions about what activities he wants to participate in. You know, I don't want him to go out for track because we think that's going to be good for him. I want him to say, "Oh, I want to do that." I know he picks his activities on the weekend. You know, he's perfectly good at communicating, "Here's my motorcycle jacket and here's the key." You know, "let's go." He tells me all the time, "Let's go for a walk. We're going to walk here. We're going to walk there." But I don't see us preparing him for that, adequately, me, as a parent, or the school.

Summary of Causal Conditions

In summary, causal conditions were conditions that had a direct influence on the phenomenon. Put differently, the phenomenon would not exist in the same way without the influence of the causal conditions, which often have multiple dimensions or properties. Table 2 reviews the multiple dimensions of the causal conditions that were discussed in previous sections, and it identifies which families emphasized the influence of each of the causal conditions.

The central phenomenon that has emerged from this data will be discussed in greater detail in the subsequent section. This component of the theoretical model will be defined, a brief account of how the central phenomenon was identified will be discussed, and a description of how the phenomenon is connected to the other components of this model will be explained.

Table 2

Multiple Dimensions of the Casual Conditions

Values Based on Past Experiences	Views of Disability
-Value of Education (Family 1, 2, 3, & 5)	-Exposure to Disability (Family 1, 3, & 4)
-Value of Employment (Family 1, 3, 4, & 5)	-Disability Training & Education (Family 1, 3, & 4)
-Value of Independence: (Family 3 & 5)	-Conflicting Expectations: (Family 1, 2, 3, 4, & 5)
*Extended Family Involvement (Family 1, 2, & 4)	*Conflicting Value of Education (Family 1, 2, 3, & 5)
*Outside Agency Involvement (Family 1, 2, 3, 4, & 5)	*Conflicting Value of Employment (Family 1 & 5)
*Decision Making (Family 1, 3, & 4)	*Conflicting Value of Independence (Family 1, 2, 3, 4, & 5)

Phenomenon

The phenomenon has been described as “the central idea, event, [or] happening, about which a set of actions/interactions is directed at managing or handling, or to which the set is related” (Strauss & Corbin, 1990, p. 100). The phenomenon can be identified by asking the question: “What is going on here?” (Strauss & Corbin, 1998, p. 130). Each phenomenon or central idea has its own set of conditions that sustain and foster its occurrence and evolution. Based on the reports of the participants in this study, the causal conditions identified above and the values based on past experiences and views of disability resulted in a single phenomenon. This phenomenon was that *parent perspectives of the transition processes for their children with significant disabilities were based on what they wished for themselves, and that their children with significant*

disabilities reflected and were extensions of themselves. Thus, this “phenomenon” represents an explanation for the expectations that these parents had for the future lives of their children with significant disabilities, as well as the expectations they had for the services being provided to their children throughout their time in the school system.

As previously described, all components of this theoretical model are connected through the central phenomenon. The causal conditions identified previously led to the phenomenon, and the intervening and contextual conditions blend with the phenomenon to result in specific actions and specific outcomes or consequences. These latter components of the model, shown in Figure 1, are described later in this chapter.

The data used to compose this central phenomenon are presented in the subsequent sub-sections. These sub-sections are: goals and dreams for the future, child as reflection of parent, and child as extension of parent.

Goals and Dreams for the Future

The goals and dreams that parents had for themselves were projected on their children, and this happened even when a child had a significant disability. As discussed previously, if a parent grew up in a family where education was valued and they valued education for themselves, then a similar value was held for their child with a disability.

All parents in this study had goals and dreams for the future lives of their sons or daughters that reflected their own goals and dreams. Some wanted their children to go to college, some wanted their children to have jobs and be productive citizens, some wanted their children to live independently, some wanted them to be independent within their family unit, some wanted their children to be a part of the community, and some wanted their children to have friends. As they desired for themselves, all participants in the study

had one ultimate goal for their children: *happiness*. Nina, Koda's mom, stated, "*I want total happiness for him. I really do. Um, other than that? I don't know. I just really wish he could be happy.*" Rosa, Celina's mom, also shared, "*My number one goal for all my kids is that they are happy. That they are happy and that they feel that whatever it is that they are doing, they feel good about.*" Likewise, Latoya, Jamar's mom, explained:

I told you about some of the things that would reduce my stress but another thing that would make me feel a lot better, and probably the whole family is, if he is happy with what he is doing. I think that is the key. I would really feel terribly and I would be extremely frustrated if he is not doing something he wants to do, if he is not happy where he is living. That wouldn't be acceptable to me.

Similarly, Karina, C  zar's mom, described her main goal for her son's future. She explained:

He would be happy and enjoy life. That is what we have been working on. We want to make his life the best we can. You know, easy. Lucky guy you know he doesn't have to pay bills or nothing. He can go outside. We like to make his life good the best we can. He is healthy. I think he is happy.

And, finally, Maria described her ultimate goal for her daughter, Esperanza. She shared, "*I just want her to be happy.*"

Ultimately, there is no difference at the core of what these families wanted for their children with significant disabilities relative to what they wanted for all members of their family. The conflicts arise because of outside factors that influence these parents' core values and beliefs such as lack of resources, lack of opportunities, and negative experiences they have within different systems.

Child as Reflection of Parent

The theoretical model presented in this study was developed around the central phenomenon that parents' perspectives of the transition processes for their children with significant disabilities are based on the view that their children are reflections of

themselves. Along with their values of education, employment, and independence, participants discussed other opportunities and activities they did in their own lives that they felt their children with significant disabilities would want to participate in when they entered adulthood. For example, Latoya mentioned that she does volunteer work so she thought her son Jamar might want to participate in some type of volunteer work once he gets out of school. She shared, *“I do volunteer work and that is why I was thinking maybe if he wants to volunteer to do some kind of activity I could see him doing that.”* She also talked about wanting Jamar to go to church because she and her husband go to church. She stated, *“Well I think if he wants to go to church that would be great. I’ve heard different stories about people with children who have disabilities coming to church and the church’s willingness to accommodate kids.”* Latoya and her husband also get together with their neighbors on a regular basis to eat dinner. They really value being part of their neighborhood and community. She would like Jamar to participate in similar activities in his neighborhood and community when he is living on his own. She described:

So I think part of it is getting the community used to people with disabilities, in particular [Jamar’s] idiosyncrasies. I think part of it is getting to know his neighbors, find out where he lives, who’s more inclined to engage with him. I don’t want to have people who don’t want him to try to engage but I want people who are genuinely interested. I’d love to see some friends or some kind of regular dinner activity. Our neighbor in this area, we do like an every other month dinner where everybody gets together and brings a dish and it’s a lot of fun. I’d like to see him doing something like that.

Another element of this phenomenon is that parents want their children with significant disabilities to have “typical life” experiences based on what they define as a “typical life” for themselves. Again, this is affected by participants’ values that are based on their past experiences as well as by their views of disability. Maria describes some typical life experiences that she had growing up and her disappointment in the fact that

her daughter, Esperanza, most likely will never have the opportunity to participate in these experiences. She shared:

I wish she would be able to have her first dance and be able to, you know, whatever. I remember getting ready for prom and going to my graduation, my first date, talking to my mom, and her helping me buy my first dress. I will never have that with [Esperanza]. I mean I can try and manipulate it as much as possible to be normal but it is not. I think she will be with me forever and as she is getting older, she's losing her friends like when we all get older and go out and leave high school we may still stay in contact but to a point. We really don't stay in contact with our high school friends. But then we make new friends at work or at social places. [Esperanza] won't be able to do that. So we [her family] are like it.

Rosa, Celina's mom, also described what she envisions for her daughter's life once she leaves the school system. She described:

Very typical. [She would] get up in the morning, go to work, come home in the evening. Hopefully have some social activities that she can engage in throughout the week. Not every night but maybe a couple nights a week. You know weekends pretty much free to do stuff with friends or family or whatever.

For several parents in this study, having their children with significant disabilities included in general education environments was one of their top priorities when it came to the services being provided by the school district. One of the reasons they felt this was such an important part of their children's services was the fact that being included in natural, typical environments within the school would lead them to being included in these same types of environments once they left the school system. Rosa, Celina's mom, described her choice to fight for the inclusion of her daughters in general education environments. She stated:

A lot of families don't choose inclusion. We have chosen inclusion for [Celina] and [Marcella] because I think it's the real world. I think for the good and the bad it prepares them better for the real world than self-contained, protected, special ed. does.

Similarly, Latoya described why she felt so strongly about having Jamar included with his peers without disabilities. She explained:

Having him around his typical peers, is a really positive thing for him and the [school staff] would say, “we’ve got the other students to worry about” and “you’d think that he’d be better off if he were in the program down the street” but it really has been good. He has really gained some good, good skills, you know, just from watching because he does imitate. You know, he used to wear sweat pants all the time. I mean, that is all he would wear. So all he had was like five varieties of sweat pants and so that is what he wore every day. He wore a pair of jeans to school for the first time in a long, long time and I think somebody said, “[Jamar], you look good in those jeans.” And (snap) he’s worn jeans every day since. He does value what his peers say to him.

She also explained that having him included with his peers without disabilities in school was not only beneficial to him socially, but it also had an affect on the way that those students viewed people with disabilities and how their views impacted the success of people with disabilities in their future lives. She stated, *“He’s going to grow up with these kids. He’s likely going to live in [this] community. How is he going to get a job if these kids he is going to grow up with don’t know who he is?”*

Another element of this phenomenon was that parents wanted their children with significant disabilities to have their same values and beliefs. Of course, we have already established that these values and beliefs are highly influenced by the experiences these participants had in their past including their past experiences with people with disabilities. Nina, Koda’s mom, explained that in their family they have very traditional values and they want their children to have these same values. She shared:

I kind of want them to have the same values that [my husband] and I do. So, you know, we are a little bit harder on [Koda] because he is the boy. But [his sister] we’re a little bit harder on her on different things because I want her to know what the woman’s role is in a family and because we are old fashioned. It would be different than what most people look at women’s right and women’s liberation and things like that. We just view things differently in this house. And I guess it’s up to our kids when they grow up but we want to teach them our values.

Likewise, Rosa, Celina's mom, grew up in a family that was very religious. Because of this she has always had very strong religious views, and although she admits that these have changed some from when she was growing up, she would really like for Celina to have this same value of church. She explained:

We went to the church school. So I mean we were there every day. We went to the church school, we went to church on Sunday, mom and dad belonged to some different groups in the church. My life is very different, very different. Not to say that we aren't very spiritual but we are not as organized religious as we were. I'm born and bred Catholic and I always will be but I actually now attend a Lutheran church and I attend it only because of the people that I attend with. It is a very small congregation. They are very accepting of my girls and that's very important to me. I didn't find that in the Catholic Church. Church in the last two years has become a good thing to them to be involved in on Sundays. [Celina] loves it. She loves church. I'd like to say I would guarantee that [she would go] but you know right now she gets to go to church because I go to church. [My husband] is not a church go-er. My hope and my desire is for her to voice that because it is important to her that I hope they will either find someone to take her or take her.

Child as Extension of Parent

Again, the theoretical model presented in this study was developed around the central phenomenon that parents' perspectives of the transition process for their children with significant disabilities are based on the idea that their children are not only a reflection of themselves as previously mentioned, but they are also an extension of their parents. This also provides an explanation for the expectations these parents had for the future lives of their children with significant disabilities as well as the expectations they had for the services being provided to their children throughout their time in the school system. The idea that parents wanted more for their children than what they had in their own life growing up, that they wanted their children to experience more than what they experienced, and that they wanted their children to go beyond their achievements was at the foundation of this concept.

This was especially true for Nina, Koda's mom, who grew up in a family that was very dysfunctional. As previously described in Chapter IV, her family moved around a lot when she was very young, many times living in the homes of their extended family and friends. She grew up very poor, in a single parent household along with her siblings. They were on government assistance and they received their clothing, shoes, and household goods from the thrift store. They were so poor that they had no running water or electricity in their house. Because of this, Nina has a strong sense of responsibility to provide her children with more than what she had growing up. She explained:

I always swore to myself that I would be more for my children. I'd give my children more financially, emotionally. I would be involved in everything that I could with school and everything, every aspect of their lives. I wanted them to have things that I never had; toys and MP3 players now and things like that because I never had any of that. I want them to have new clothes. I want to give my children everything I didn't have.

Similarly, even though Latoya did not go to college until later in her life, she does have the expectation for both of her sons, including Jamar, to attend some type of post-secondary education program when they graduate from high school. She wants them to have the typical college experience. She stated, *"That's kind of what I've always wanted for both my kids, for them to go off to college."*

Summary of Phenomenon

In summary within grounded theory, the phenomenon is the central component of the theoretical model. The phenomenon identified in this model emphasized that parents' perspectives of the transition processes for their children with significant disabilities were based on their perceptions of their children as reflections and extensions of themselves, and as deserving of the same outcomes that they wished for themselves in life. This helps to explain how parents developed their expectations for the future lives of their children

as well as how they viewed services being provided to their children within the school system. The elements of phenomenon are shown in Table 3 along with which families stressed what element.

Table 3

Elements of Phenomenon in the Theoretical Model

Child as Reflection of Parent	Child as Extension of Parent	Goals & Dreams for the Future
-Wanting their child involved in same activities as parents (Family 1, 2, 3, 4, & 5)	-Wanting more for their child than they had (Family 3 & 5)	-Going to college (Family 3 & 5)
		-Getting a job (Family 1, 3, 4, & 5)
-Wanting their child to have a “typical life” based on their own definition (Family 1, 3, 4, & 5)	-Wanting their child to experience more than they did (Family 2, 3, & 5)	-Living on own independently (Family 3 & 5)
		-Independence within the family (Family 1, 2, & 4)
-Wanting their child to have their same values and beliefs (Family 1, 2, 3, 4, & 5)		-Being a part of the community (Family 1, 3, & 4)
		-Having friends (Family 1, 3, & 4)
		-Happiness (Family 1, 2, 3, 4, & 5)

Intervening Conditions

Intervening conditions have been described as conditions that “mitigate or otherwise alter the impact of causal conditions on the phenomenon” (Strauss & Corbin, 1998, p. 131). They are indirect factors that impact participant expectations for their children or, in some instances, alter these expectations for the future lives of their children.

These conditions were typically not directly associated with the participants’ past experiences or their views of disability, but served to either support their expectations and views, or presented barriers to these expectations for the future lives of their children. The intervening conditions identified by these participants included experiences with systems, availability of resources, and availability of opportunities.

Experiences with Systems

The first intervening condition that either helped to support or mitigated the participants’ expectations for the future lives of their children with significant disabilities or altered their views of disability was their experiences with different systems. Often parents of children with significant disabilities had experiences within different systems because of the extensive needs of their child. These experiences typically began in the medical field and then shifted into the school system once their child was old enough to go to school. These experiences were not directly associated with participants’ past experience, such as whether or not they attended college, but either supported or changed these expectations in some way. These experiences might also have been associated with how these participants viewed disability in general. The following experiences with

systems will be discussed: experiences with medical systems, experiences with school systems, and experiences with adult agency systems.

Experiences with Medical Systems. Several of the participants in this study had experienced receiving services in a medical facility for their children with significant disabilities. Some of these participants had been involved with the medical system since the birth of their children. Their experiences ranged from their children being hospitalized for several months at a time to being monitored and cared for in an out-patient treatment basis. Despite the location or intensity of the care their children were receiving these participants had negative experiences within this system that affected their expectations and views.

Rosa, Celina's mom, expressed the frustration she experienced within the medical field. She shared, *"There is a lot of frustration with the medical community although there has always been frustration with the medical community. Whenever you are dealing with specialty care, there is frustration there."* Some of this frustration was due in part to the medical model of treatment their children with significant disabilities received that were interpreted as negativity and low expectations from medical staff. Maria, Esperanza's mom, explained how medical staff made her feel when her daughter was receiving intense treatment. She stated:

It was really hard because they were always negative. You know, they were always telling me "she is not going to amount to anything; she's going to be a vegetable, she can't think, talk, walk, or anything and she can." That was really difficult. In the medical arena, it is either the parents' fault or something else. It is such a negative environment.

Karina, César's mom, also experienced these negative attitudes and low expectations for her son from medical staff. She described what she was told by her son's doctor in Peru

when she first found out about her son's disability as well as in the United States. She explained:

I think he is a normal kid until one day I went to a different doctor and as soon as [he] saw him he said, "Oh your son is dumb." And it was hard because I was young. Even here they keep telling me, "He can't do anything." And I say, "No I know him. I know for sure that he can do more than you are expecting from him." So yeah it was kind of hard here and in different countries.

Maria, Esperanza's mom, felt like society puts medical staff on a pedestal so whatever they say is what people believe is true about children like her daughter. She feels like the low expectations and negative attitudes for her daughter began in the medical field. She shared:

She has been through a lot. They treated her like a guinea pig. They are the ones who wanted to give up on her and they are the ones that kept telling me, "Spare her, her dignity. Let her go." We put people on a pedestal unfortunately especially in the medical field. We put those doctors on a pedestal and believe whatever they say as truth.

Because of these experiences in the medical system these participants' expectations of what their children with significant disabilities would be able to do in the future and their views of disability in general were altered. This was especially true for Karina, C  zar's mom, who several times stated that they could not expect much from their son. This message was something these families had heard over and over again from people who are viewed in our society as very knowledgeable and respected. The unspoken message was that your child will not be able to achieve the goals and dreams that you once had for him/her.

Experiences with Educational Systems. Along with the experiences participants had with medical systems, they also had experiences within school systems that had an impact on their expectations for their child's future life, as well as the way they viewed

disability in general. These experiences consisted of negative events that took place in the school environment or negative attitudes of school personnel, feeling powerless, and the bureaucracy of special education.

Several participants experienced negative events or negative attitudes from school personnel during the time their son or daughter was receiving services. However, two participants in particular experienced major events that had enormous impact on their views and expectations for their child. As previously described in Chapter IV, Esperanza was restrained and put in a closet at school which resulted in her receiving a traumatic brain injury. Maria described:

She got hurt at school. [Esperanza] hasn't told us what happened. Our understanding is she had a stroller and they strapped her to her stroller and stuck her in the closet with the stroller and somehow the stroller tipped over and she fractured her head in four different places. That's the story they say but when she went to the hospital the doctors said that's impossible. I can't imagine what really happened. So that was really hard because it was like the system failed her again and what I mean by that is when she was in the hospital the system failed her there too and we had a really hard time within the hospital and we had a really hard time with the school system. We sued the school district. There was like seven years where we fought. [Esperanza's] case did change a lot of laws to protect kids like [Esperanza] but the one thing it didn't do was to help us support [Esperanza] for the rest of her life.

Because of this experience, what Esperanza was capable of doing changed, thus, Maria's expectations for her daughter changed based on her current abilities. She shared, *"We came from a bad situation. We came from a school district where she sustained a severe head injury and is now a completely different kid."*

Also, as previously discussed in Chapter IV, Karina, C  zar's mom, experienced a negative event with her son in a school district when her family decided to move. She felt like she had done all the necessary preparations for C  zar to attend and receive services in the new school district. However, the school district told her they could not provide her

son with services in a school-based program and pushed for him to be placed in a special segregated school for children with significant disabilities. She recalled:

We move and the school wasn't even prepared. They don't have equipment. They don't have anything even though I told them. They send him home right away and it took me two years fighting with the district trying to get services. They put him in home bound and home bound doesn't work either. You know when the teachers were saying, "Oh yes I think [César] is getting improved." I don't know how they can change their mind but the next meeting they say, "Oh no he changed again. He can't be at school." Every single person that worked with him in that district keep telling me, "Oh no we can't work with him. He can't sit for twenty-minutes. He can't do this. He is so dangerous for the other kids and the other adults and the teachers." I said, "He can't change from a couple weeks since Christmas break." They don't want to serve him. That was a nightmare. They say, "Oh yes we have all the services." But believe me since day one they told me that no he is not the type of kid that would be included in anything in the district. I told them no because he was working with the other school district and he was working fine. He was able to learn to stay in a room with kids, even included in the regular classroom, but they keep telling me no. They say no in my face. Even the principal going and knocking on my door and threatening me that they are going to expel my son from education and ever since then they don't serve him. They wanted to put him in a home bound service. They put him in a special school. They have kids that stay there and their parents just leave them, like being in jail. It didn't last too long because I take him out. So they threatened me again and say if I don't leave him in there he is not going to have service and I keep fighting. I didn't like the school and the way that they treat the kids. You know the punishment that they have. They just punish him. They put the kids in a little room. They said because it is safe for them. Like there are no windows or anything so they can't hurt themselves. They can't see outside. They have a little window in the door so that they can see what they are doing. But he was not used to it. It just was kind of too harsh for him so I take him out and they never serve him you know since day one so we moved back.

Because of this experience, Karina admitted that she was happy with the services her son was receiving in the school district when they moved back, even though the services were not necessarily appropriate for her son and didn't necessarily align with the expectations they had for César; his parents were just happy the school district wanted to provide him school-based services.

Similar to Maria and Karina, Nina, Koda's mom, also felt like her son's experiences in the school system had not provided him with skills he will need to become successful. She felt like many of his problems existed not because of his disability, but were a side effect of the school's low expectations. She explained:

I hate to put the school system down but the reason my son is the way he is, is because of the school system. He is not up to the standards of all the other children that are in the community. They never strive to teach him anything. So that's where he is learning the learned helplessness. So that is what the school has done to him. I started going to the IEP meetings and I kind of really made them buckle down on him. But they will buckle down for a month or two and then back to the same old thing. It is just easier to push him aside. He doesn't know anything and he can learn. He can but he doesn't know anything because the schools just let him get away with it.

Because of this, Nina felt like her son would never be able to achieve some of the dreams that they had for him. She stated:

Graduating from school and enrolling in college or moving out and getting a job, I know that the likelihood of that for him is slim to none. I know that. You know at this point it is kind of too late because I stepped in kind of late in his life and by then the damage had already been done.

Along with negative experiences, often parents reported experiencing feelings of being powerless over the services provided to their children and over decisions made by school personnel in regard to their children. Rosa, Celina's mom, reported not feeling like a powerful partner when it came to her daughter's educational services. She explained:

I'm not sure that we felt like a powerful partner. I don't think we felt as powerful a partner as the law seems to lead us to believe we could feel like. Because it's like those very empowered young teachers, when they leave college and they're all excited to get in there and save all those kids. And they get in there and hit the bureaucracy of the district and before long they are doing just what they are told to do because they have to. So it's the same. You read the law and you go, "Wow, yeah, you bet. Wow." You talk to the people at the legal center; it's like, "Yeah. Right." Then you get to the table, "Well, we can't do this." They don't have the money for that. You know, and you just kind of go, "Okay." So it's with some pretty good reason that I kind of go, "IEP time? Okay. I'll be there. Okay bye. See ya." I just don't put a lot of stock in it. I

should say I am grateful that we have the right if we absolutely had to, but you know, as a parent in this society, you have to pick and choose your battles too.

Maria, Esperanza's mom, also reported feeling like she had no power over the school district even after her daughter was injured because of their actions and decisions. She stated:

There's no mechanism to go after a system. They blamed [Esperanza]. They said, "[Esperanza] was hitting them and biting them and doing this and doing that and they were trying to get her to calm down and they had to put her in her chair, the chair fell over." So the cops came back and said, "there is nothing we can do you're lucky they take care of her. You're lucky they allow her to go there." In the public school system we had a really hard time because here is this mega system and no one can touch them. No one can do anything to them and even though they do wrong. I mean the hospital did so many things to [Esperanza] it's unreal and I don't mean the hospital itself, the people who have worked within the hospital have done so many things to her and the same with the school system I'm tired of [Esperanza] being the guinea pig of the system because she has been her whole life; medically and educationally.

Karina, César's mom, also felt like when the school district refused to provide school-based services to her son, they had no power over that decision. She recalled:

We would have liked to but we don't have the money to sue and hire a private lawyer. It was easy for them to dismiss us. We just have to wait and we don't have the lawyer so there was nothing we can do. [César] missed two years of school for nothing. So we decided to sell the home and come back because we even decided to go to court but of course we didn't have the money to have a private lawyer so we had the legal center for kids with disabilities. The legal center talked to me and he talked to the judge and the judge said because they were the county school district, there was no way I could win anything and that I should just back out. So that is what we did. We sell the home. I put the sign up the next day and we moved back.

Because of the experiences of feeling powerless over educational experiences and services being provided to their children with significant disabilities in the school systems, participants' expectations of services and supports for their children's future life were changed, and thus their expectations for their children changed.

Finally, several participants reported experiences within the school system that focused on the bureaucracy of special education. This bureaucracy consists of the organization and structure of educational programs, official procedures, and school practices specifically designed for students with disabilities. Latoya, Jamar's mom, is very aware of the bureaucracy of special education not only because of her sons' experiences but because of her job. She shared, *"I have been thinking, what's the best way to create some change because when I see how special education is being implemented versus the law and intent of the law, it is two very different things."* Rosa, Celina's mom, also reported feeling frustrated with the bureaucracy of special education. She admitted that this frustration has affected her relationship with school personnel, thus affecting the transition planning process for her daughter. She explained:

I think the most aggravating thing for me is that if you squawk you stand more of a chance of getting what you want but you only get it for yours. You never make any roads into what's best for other kids and like I said, about ten years ago there seemed to be a glimmer and I really felt that all the fighting I was doing for my girls was having an impact on what other kids were getting. The best part of the transition process is the anticipation of just being done with public schools. That's the best part that we are almost done with public school. The public school system now, as far as I am concerned, has some major, major problems. That would make it tedious for any parent not just parents of kids with special needs.

Latoya, Jamar's mom, also felt like she has been worn-down by the bureaucracy of special education. She stated, *"I've been worn-down by this system. Well, it's you know, year after year of the same system that is not effective and not supportive and that is not good."*

Experiences with Adult Agency Systems. All of the parents in this study had some experience with adult agencies and they reported several characteristics of these systems that had an impact on how they planned for the future lives of their children. For

example, Maria, Esperanza's mom, had met with several different adult agencies that provide services to individuals with significant disabilities in an effort to find services for her daughter once she leaves the school system. One of her main concerns with many of these agencies was the fact that they do not hire people who have any qualifications to work with individuals with her daughter's level of need. She stated:

I think they hire people and they don't pay people good. No wonder they don't find people because they don't pay them anything. I think if they required people to have certain qualifications they would make improvements. They don't have hardly any qualifications for hiring. I mean it is just whoever. To be a certified aid all you have to do is learn how to give meds and you just go take a class but I think if they actually did background checks, certifications, and required certain levels of education and pay them for that. I think it would be safer.

Another identified concern of adult agency systems was the fact that there were limited options available when it came to post-school services for individuals with significant disabilities, especially those who require a higher level of support. Karina, César's mom, explained:

The school prepares you in planning. "What are you going to do? Graduation is approaching, did you think about it?" So we visit a place and every time we visit one place it is like disappointing because it is not what we are expecting. It's hard because there are not too many options unfortunately. So I say okay we have to make a decision. May is close and you know he is not going back to school anymore. Yeah it was tough but I think we make the right decision because if he is not going to be doing anything I would rather have him with us doing nothing.

Maria, Esperanza's mom, also felt like the post-school options for her daughter were limited. She stated, *"It's been really hard because, you know, there are not very many options for children like [Esperanza]. There are options for people with disabilities but for high functioning people."*

The next concern identified by participants was that adult agencies are not guaranteed services. This is often a shock for many parents who come from the school

system, where services are mandated for all identified children, into a system where the availability of services is based on more specific criteria and limited funding, and where, as a result, not every individual qualifies for services. For example, Rosa, Celina's mom, was concerned that even though they have their family business, where they are expecting their daughter to work after she finishes school, she will still need support through an adult agency to get her to be productive in the job. Her concern was with the fact that these support services might not be available. She explained:

I think the only thing might be that we can't get the supports we need for her to do the job we have for her. In other words if they would come back to us and say, "Oh we can't travel that far" or "No we can't send our people outside of the county" or something like that. That is going to be problematic. But I think unless they change the law drastically, there are enough teeth in it to get what we need to get her working.

Another issue raised with adult agencies was the fact that their services are not always based on the individual needs of the person but are based on how much funding they have or on the program that is already in place for the different levels of need. This is a concern for Latoya, Jamar's mom. She shared:

I'm thinking he's going into that system that I just can't stand. That is so, "this is what we have and this is what you are going to get." Rather than, "oh, he only needs this or he needs this and this." It's going to be very un-individualized and I think, if it's not a good fit, it's going to be really bad for him. It's not going to help him become independent or to continue learning. I think it could be kind of traumatic, actually. What I'm hearing is, remember how I talked earlier about the segregation? You know, "if you're this disabled, you get this service." I sense that some of the services that would probably be good for [Jamar], they might say, "well, he's too disabled to access that service." Rather than saying, "well, there probably can be made some changes and if we did this instead of that." That's my concern. I know there are a lot of parents that have a lot of questions about the adult services. It makes me really leery of involving the adult systems with him and my thought is the less adult support he needs, the better off he's going to be.

While concerns exist, Rosa, Celina's mom, felt like her experiences with adult agencies had been overall positive. Because she had already gone through this transition process with two of her older children, she has had to be involved with these agencies to provide them support in their post-school life. She felt like she had much more control over the services her children received from the adult agencies and looked forward to not having to deal with the school system anymore. She described:

Transitioning out the school system is going to make life better because from my experience the adult system has been so much easier to navigate. I have had only good luck with the adult system but my oldest daughter has needed very little. Now, [Celina]? I don't know what that experience will be like because her needs are going to be quite a bit different I think than my oldest daughter and I think we are going to need more support with [Celina]. So far the adult system, I have felt so much more in control and I just felt so much more satisfied with that experience than the educational experience. I was really looking forward to getting my kids out of high school. Really looking forward to that.

Some participants changed their expectations because they found that there was not the same availability of support in the adult system that they have grown accustomed to in the school system. Some changed their expectations because they did not want to get involved with yet another system that is not going to take into account their child's individual needs. Some based their expectations on the fact that they have already gone through this system and have had positive experiences. Thus, because of these experiences with adult agency systems, participants' expectations for their children's future lives were influenced or altered.

Availability of Resources

The next intervening condition that either supported or altered the participant's expectations for the future life of their child with a significant disability or had an impact on their view of disability in general was the availability of resources. Often parents of

children with significant disabilities have to rely on their own resources in order to ensure they are meeting the expectations of their children's future lives. The more resources available to and within the family, the more likely they will be able to reach their expectations and goals. On the other hand, limited availability of resources can prevent them from reaching those expectations and goals that they have for their children's future lives. The following resources were identified as having an impact on the process of planning for the future life of their child: time, money, knowledge, and support.

Availability of Time. The first resource identified as having an impact on the planning process for the future lives of their children with significant disabilities was the availability of time. They defined this as having enough time to care and provide the kind of life they want for their children. Maria, Esperanza's mom, would like her daughter to be able to participate in their community and she tries to ensure that this happens by taking her on outings on a consistent basis. However, in order to make this happen, Maria must devote several hours just to getting Esperanza ready to go. She recalled:

Getting her ready for the day to go do something is very time consuming. It takes at least a couple hours to get her bathed, fed, dressed, meds, her nebulizer, her oxygen, and getting all her books and her bag ready to go. So that takes at least a couple hours. It is time consuming. I mean there are times that I am like, "I wish I didn't have to do this today" but we do because I know that it benefits her.

Karina, César's mom, also felt like her availability of time was a big factor in whether or not her son was able to participate in activities that could add to his quality of life.

Because of her limited amount of time, often her son was not able to participate in activities outside of the family home. She explained:

He played soccer before and I was the one working with him, you know. I hold his hand and I run with him for the soccer. Bowling yes he can bowl by himself as long as he has the ramp we just help him to put the ball and he just push. But

those are the little things you know we don't have the time. We can't just drop him off. Unfortunately we don't have the time.

Because of these parents' limited time, they were not able to provide their children with the type of activities and experiences they would like for them to have. Thus, due to these limitations parents were forced to alter their expectations of their children's future lives.

Availability of Money. The next resource identified as having an impact on their planning process for the future lives of their children was the availability of money. They defined this as not having enough money to provide their children with the services and supports needed to meet the expectations for their future lives. Maria, Esperanza's mom, described her frustrating financial issues with having to pay for her daughter's medical care. She said:

[Esperanza] has never got medical support until she was almost eighteen and the only reason why she finally got it was they did away with the parents' income. You know, I couldn't afford to keep [Esperanza] home. She gets transfusions. She gets IVs. She has pumps all over the place. She is on oxygen. I mean the normal life that I live I wouldn't be able to keep her. I wouldn't be able to support her and so I would have to quit work. Ironically they told me, "Why don't you just quit and get social security for her. You will get Medicaid that will pay for everything," but what about my life and my family and my home? I don't want to live like that. I don't want to have to depend on a system. I do need to depend on a system to help me with her medical stuff. I don't want them to support me. Families put their love ones in places and they can't afford them. You know people don't get it and then now she turned eighteen and she got social security and I am like, "wow she gets social security." So it pays for her stuff and it's not about that. It is about trying to get help for her and like now that she is an adult it is different. She still has to pay. I mean I pay over four or five hundred dollars in co-pays. That is a lot of money you know.

Karina, César's mom, also reported the fact that availability of money was a huge factor in the amount and quality of services her son would be able to receive after he left the school system. This was very stressful for their family. They would love to provide their

son with more opportunities to participate in post-school activities but they cannot afford the services they would like for him to receive. She explained:

We knew how it was going to be once school ends and it changed for him. The fees are also high for the kids that have to go every day. Tuesday and Thursday are the days he is going right now and sometimes he has weekends. Once a month he has a weekend. Yeah so they went out Saturday. They just go to a movie or bowling or he just hangs out with friends. I know he wants to go out and play and enjoy but you know it is expensive so we have to do two days and then we try to have one more day and we are not getting it. So some day we will be able to get one more day. But still it is three days out of seven pretty much, you know, for the time that they get will depend on if he can qualify. Of course having that individual program is more expensive than having you know, a group of ten or twenty people. So I don't know. I probably was expecting more. The only thing that we was looking for like I said before is to find a nice place for him. We didn't expect the services were so expensive.

Nina also had concerns about the amount of services their family can afford for their son, Koda. He was also only going to be able to receive services a few days a week which was going to place a lot of stress on the family. His mom described:

He'll go three days a week because that all we can afford because each adult has their own budget. I think full time services would be good. Being in the group home would be really good. That would give us a little bit of a break from him and then we can handle things.

Availability of Knowledge. Another resource identified as having an impact on the planning process of the future life of their children was availability of knowledge. They defined this as having the knowledge of their rights within the adult agency arena, knowledge of community resources, and having the knowledge of where to begin the transition process. When Latoya, Jamar's mom, was asked if she knew what her rights are under adult agencies, she stated:

No. I really don't and I don't know if they just wait until you get to that age and then, "oh here, by the way, here are your rights." I'm thinking things like voc rehab, I have no clue how that agency operates but I know that he will be involved in it.

Although, Rosa, Celina's mom, had been through the transition process before with two of her older children, she still admitted she did not know about all the available resources. In particular, she was unsure of what resources were available for her daughter if she was unable to work at their family owned business. She explained, "*My thought is the DDRC. I need to see what they have in terms of a day program. I mean I don't know. I haven't looked in to see what they have available.*" Latoya also described her feelings of being overwhelmed by everything that she needed to know in order to help her son have a successful post-school life. She shared:

I see him having some kind of engagement where, you know, when he is not working or not going to school he is doing an activity. I really would like to see him with some close friends. I would love to see him get married. But, you know, I'm not quite sure how that is going to work. I don't know how those steps are going to happen. What they are going to look like. I am almost overwhelmed when I think about it. There are so many steps it's daunting.

Having the knowledge of their rights within adult agencies, being aware of resources in their communities, and having the knowledge of what they need to do in order to help their children have a successful transition out of the school system and into their future lives was important in the planning process of these parents and was something that could affect what they were expecting for the future lives of their sons or daughters. They will not be able to sufficiently plan and prepare for their children's future lives without this important knowledge.

Availability of Support. The final resource identified as having an impact on the plans for the future lives of their children with significant disabilities was the availability of support. Participants defined this as having someone available, be it an individual or a program, that will provide services to their children in some aspect of their life. Several of the participants reported feeling like there were not enough supports available to

adequately serve the future needs of their sons or daughters, especially if they have higher levels of need. Maria, Esperanza's mom, stated:

I don't think the system has enough supports to handle people like [Esperanza]. I've been part of transitions since I have been working for the school district in the transition program and I have seen great transitions for higher functioning kids. But we had a meeting about [Esperanza's] transition and I feel like [Esperanza] falls through the cracks because they don't know what to do. It is not like they don't want to try but her transition is, "Well who is going to take care of her now?" So there is not that support.

Karina, César's mom, also felt like they do not have anyone to support their son. Because of this he was not able to do many of the things they would like for him to participate in. She shared, "*So we don't have that support. We don't have a person that we can say, 'Okay, you know, just go and do this with him.'*" Rosa, Celina's mom, has had a lot of experience working with families who have children with disabilities and she agreed that many parents have a difficult time trying to find supports for their children once they leave the school system. She explained:

From what I gather, parents are scrambling. I mean I have other friends. I haven't asked them specifically if they have somebody at their staffing but I know they are scrambling to find services, especially because of the waiting lists they know they aren't going to get services right away so they are looking for anything they can get.

Latoya, Jamar's mom, also felt like she was limited in who she could rely on to provide support to her son. She was concerned because she did not feel like her extended family was available to provide support, and she did not feel comfortable asking her friends to provide support, as discussed earlier in this chapter. She stated:

I am almost thinking I don't want to burden a family member with the responsibility of caring for him and they may not have the same goals. So I mean that almost gives me more impetus to get him ready for independent living rather than to be reliant on anybody else.

Sometimes even when families sought support from adult or community agencies, the supports for children or adults with more severe needs were not available. This is true for children like C  zar. Karina, C  zar’s mom, shared:

When you call and they said, “Oh yeah, but what kind of support does he need to go?” Well he needs to be with someone 24/7. “He can come but someone will have to come with him.” We don’t have someone who can take care of him because the ratio is like one person for four kids so they don’t have time for just one person. It cost a lot to have just one person for one kid. It would be good to have more choices because like I said there are a lot of choices out there but for kids that don’t do anything. Of course they can go and they will be sitting in their wheelchair and they won’t do anything. So they can just be watching and do nothing. All of the other kids you can tell them, “No you can’t do that.” Or they go and they eat or “Go and get your food and eat.” So they can get anything they want. They can sit down to eat and everything. But there’s nothing for those that need more help. You have to go with him and get him a plate and say, “Now eat” or feed him. So he has to be with someone all the time. So it would be nice if there was something for those kinds of kids, the ones in the middle.

Having enough supports available to provide adequate services to their children with significant disabilities was important in the process of planning for the future. This factor also had an impact on parental expectations for the future lives of their sons or daughters. Without enough support available, these families will not be able to sufficiently plan and prepare for their children’s future lives.

Availability of Opportunities

The final intervening condition was the availability of opportunities. Limited availability of opportunities can prevent these children from reaching the expectations and goals that their parents have set for them; inversely, the presence of life opportunities can enhance the realization of parents’ expectations and goals. The following opportunities were identified as having an impact on the process of planning for the future lives of these children: employment opportunities, post-secondary education

opportunities, independent/supported living opportunities, and recreational/social opportunities.

Employment Opportunities. The first area of opportunities identified as having an impact on the planning process for the future lives of their children with significant disabilities was opportunities for employment. Several participants had expectations for their children to be employed once they leave the school system. Unfortunately, many of the options for employment for individuals with significant disabilities were limited. These limited options consisted of employment that did not pay well, only part-time employment, work experiences in segregated settings or programs, and work that was demeaning. Maria, Esperanza's mom, described how she felt about the employment option available to her daughter through a local adult agency. She shared:

We looked at a sheltered workshop but it reminds me of a warehouse. I mean I think it's good for certain people but [Esperanza] couldn't handle it because there are just so many people and so much noise. People are just all over the place. I have a cousin that goes there and she works and I'm sorry but she only gets like two or three dollars a day and she works like so many hours a week and I think that is like taking advantage. So I have a really hard time with that personally.

Latoya, Jamar's mom, also expressed her frustration with the employment options available for her son. She felt like there were limited opportunities for engaging employment and that the options that were available to her son would not be full-time. She stated:

He's more engaged when it's something that he's interested in as opposed to something that somebody says, "you'll be really good at this, [Jamar]. Go out there and do it." So that's why I was thinking about the school employment and some of the options that they have been throwing out. I'm thinking, you know, "but will he be engaged?" I don't know that he really wants to sort the recyclables at the retirement home. I want it to look like he's going to work doing something productive. What I think it might look like is maybe three or four hours a day of employment because I think the expectations are kind of low. "Not full-

time work. Oh no, probably part-time work.” I know it’s not what I want for him but it is what’s out there.

Finally, Rosa, Celina’s mom, expressed her concern regarding the types of employment options available to individuals with significant disabilities. This concern was a major factor in their family deciding to start their own family business where their children with disabilities would be able to participate in successful work experiences. She explained:

They wanted to place her in a flower shop. They wanted to place her in a daycare center. They placed her in a daycare center where they wanted to take care of her. They didn’t give her jobs to do. I’d going to pick her up and she’s just sitting there with the rest of the kids being taken care of and I finally went to the teacher and I said, “It’s not a job. That’s somebody watching her for two hours so you don’t have to watch her.” I said, “That’s not a job.” So then they wanted to put her in a flower place. It wasn’t a flower shop. It was some place where they took care of flowers and I went over there and there were three or four other people just like [Celina]. It was like the typical food, filth and flowers. You know, it was all they could think of, janitorial, fast food, working around flowers and I said, “No, that’s not for her.”

Because of the limited opportunities for employment available to individuals with significant disabilities, these participants were faced with barriers to finding their children successful employment experiences once they leave the school system. This may prevent these children from reaching the expectations and goals that their parents have for them, thus, preventing these families from sufficiently planning and preparing for their children’s future lives.

Post-Secondary Education Opportunities. The next area of opportunities identified as having an impact on the planning process of the future lives of children with significant disabilities was opportunities for post-secondary education experiences. Not until just recently has there even been an option for students with significant disabilities to attend some type of post-secondary education program. In recent years, programs specifically designed for these students on university or college campuses have begun to

emerge. For Latoya, Jamar's mom, this option was something that she has always wanted for her son. However, she did not feel like the school had even considered this option for Jamar or for any other student who had gone through the Life Skills Program. She shared:

I'd like to see him go into some vocational training. Some post-secondary training, I think that would be so good. That's my dream. So that's what I'm pursuing because it would be great to not only have him getting some post-secondary training but also some independent living training at the same time. I think once he gets a taste of it, he's not going to want to come home. I read about the College Living Experience through an article. Another university program I actually heard about from another individual who I happened to approach and said, "Hey, you know, I know that there are some programs out there." I also heard of a program out at UCLA that did something similar. You know, that's the college track and to know that that's still an option I'm glad to pursue it. But I have not heard anything like that from his teachers. In fact, I was going to give my College Living Experience materials to the special education teacher so that she could take a look at them. Maybe even see those as viable options for some of the other students in his class.

Independent/Supported Living Opportunities. The next area of opportunities was for independent or supported living. This was defined as having supports in place to live as independently as possible. Unfortunately, many options for independent or supported living were limited and it was not just as simple as finding a place for their children to live. There is much more preparation that goes into helping these students be able to successfully live independently or in a semi-independent situation. Latoya, Jamar's mom, described how she felt about getting her son ready to live independently, which is an expectation that she had for him. She stated:

For me it is more important to get him ready for independent living rather than to be reliant on anybody else for support. However, somebody is going to have to check on him and make sure he is washing his clothes, doing the dishes. Somebody almost needs to be there to make sure that is what is happening. He's got to learn to use transportation. He has got to be able to communicate over the phone so that if he needs something or if he has an emergency he can call. So that has always been a big one of mine.

Another issue facing families with children who have significant disabilities is the fact that many options for independent or supported living situations are accompanied by an extended period of time on a waiting list. Rosa, Celina's mom, described how this will affect the plan of having someone available to help her daughter live more independently within the family home. She explained:

[Celina's] on the waiting list for adult services, Supported Living Services in particular. My older daughter got right into SLS. Now there's a waiting list. They are telling me it could be five years before [Celina] gets in. Supported Living Services, SLS, through the Community Center Board, would allow us to hire people to do some community participation stuff, to do some personal care, stuff like you know laundry, and that kind of stuff. Continue to support her to be able to help her do that at home but you know she's on the waiting list for that. That is not just definitely guaranteed funding when she leaves school. She has to be on the waiting list for five years and, you know, that is totally dependent on the legislature and how much more funding they make available for those programs.

The waiting list was also a concern for Nina, Koda's mom, who had an expectation for her son to move out of the family home once he graduates from high school. She stated:

They told us, "The waiting list for the group home is anywhere from ten to fifteen years." I said, "I want him put on the list. If at that time in ten years we decide that is not what we want then we will change our mind and you can move to the next person on the list." And they were like, "Well are you sure because it is going to be forever and the chances of him getting in there are slim," just trying to discourage me. I said, "No we want him put on the list." So he's on the waiting list for the group home.

Recreational/Social Opportunities. The final area was opportunities for recreational and social experiences. All of the participants in this study had expectations for their children to be involved in some type of recreational or social experiences once they were finished with school. For example, Maria, Esperanza's mom, described an option she found available for her daughter once she is finished with the school system. She described:

I found an agency that takes adults fishing and stuff like that. They take them out in the community and that is what [Esperanza] would like. She would like being out in the community. They do community things and then they teach them some skills. It is fewer people, fewer clients and I think she would like it a lot better because it is more open. It is not as chaotic and hectic. In the summertime they have a lot of camps. So that is kind of what they are offering.

Similarly, Karina, C  zar’s mom, found social activities that her son could be a part of through their community center board. However, because her son needed a full time support person she was not able to have her son participate in these activities. She explained:

You know the community center board has as a lot of flyers that they send. They say “Oh we are going to be bowling these days and we are going to be in this place.” But we can’t send him because he needs someone to be with him and we don’t have that ability and if we don’t have the time to go, we can’t let him participate. You know, oh yeah, I would be willing for him to be involved and be more active and they have more choices to do other than for him to be in his bedroom playing with his cars but there is nothing. There is no choice. There is nothing that we can say, “Oh yeah you want to go.” No, I tried. I been you know asking for camps. I’ve been asking for activities. But he is not independent so he won’t be able to go. That is why I have my hands tied because there is nothing that he can do. I have other kids that I have to raise. I do a lot of activities with him here at home and at least being with him and talking but again, you know, a better life with more activity and more choices. It is just that we don’t have the ability to do that if there are no choices out there.

Rosa, Celina’s mom, also expressed her expectation that her daughter would be involved in some type of social activities once she leaves the school system. She had found programs through different adult agencies that would be available for her to participate in once she is finished. However, Rosa was concerned that there were not a lot of options available, and that Celina would end up not having an active social life. She shared:

Hopefully she will have some social activities that she can engage in throughout the week. Not every night but maybe a couple nights a week. You know weekends pretty much free to do stuff with friends or family or whatever. She is going to be more of a stay up in your room, watch TV kind of person. So it’s going to require

whoever is around her to kind of push her into more extra activities. She has a boyfriend. I think I mentioned that to you before and they don't do much together mainly because his mom works, I've always worked, I'm now involved with this new challenge of mine. So, we don't have the support to bring them together as often as they would like to. She seems to be very happy but she doesn't have friends coming over. You know, she's not invited anywhere. So [Celina's] social life, pretty much, is her family. My challenge is going to be to find people during the day that aren't working that I can either pay or beg or whatever to go take them to do stuff but if not, they will be here at home.

Nina, Koda's mom, was also concerned that her son was not going to have a social life once he graduated from high school. She has enrolled him in a program through their local community center board but felt like this was the only option available for her son to participate in anything social. She stated:

They do an activity day where they go bowling or things like that. He says he enjoys it. He looks forward to going. So I guess that's the only social interaction he has. Other than that, it's just us. He has no friends. He doesn't go out. For him to be entering adulthood without any of those experiences, I'm a little concerned. So, I mean, he really doesn't have a social life.

Latoya, Jamar's mom, also expressed that she would like to have her son involved in recreational or social activities in his future adult life. Unlike the other participants, she would like for these experiences to take place in more of a natural context. Unfortunately, she felt like in order for her son to be involved in these types of activities she would have to get them through a segregated community program for individuals with severe disabilities. She explained:

I want it to look like he's engaged in some recreational or social activity after work. I really would like to see him with some close friends. I would love to see him get married. But I'm not quite sure how that is going to work. I don't know what those steps are going to look like. I know a lot of it is going to be building social skills. I think part of it is getting the community used to people with disabilities and in particular [Jamar's] idiosyncrasies. I think part of it will be just getting to know his neighbors, find out where he lives, you know, who's more inclined to engage with him. You know I don't want to have people who don't want him to try to engage but I want people who are genuinely interested. Those are the things that I foresee. Unfortunately, I think it is going to be some

kind of recreational activity or social program for people with disabilities that may not be so community based but just a separate group. It's not what I want for him but it is what is available.

All participants had expectations for their children to be involved in some type of recreational or social experiences once they are finished with school. Unfortunately, most of the opportunities for social or recreational experiences for individuals with significant disabilities were limited to segregated programs with other people who had a similar disability label or with immediate family members. Because of these limited opportunities, individuals with more significant disabilities often do not develop friendships leaving them and their families feeling isolated and secluded.

Summary of Intervening Conditions

In summary, the intervening conditions were those indirect factors that helped to create or sometimes alter parental expectations and goals for the future lives of their children with significant disabilities. While not directly associated with participants' past experiences and their general views of disability, intervening conditions either provided support for or presented barriers to their expectations and goals for the futures of their children. These conditions also contributed to participants' need to take action or interact in some way in order to eventually reach their expectations, break down barriers, or accept their current circumstances. In this theoretical model the intervening conditions that were identified included experiences with systems, availability of resources, and availability of opportunities. These are summarized in Table 4 as in previous sections, families emphasizing partial conditions are identified in parentheses.

Table 4

Intervening Conditions Affecting the Casual Conditions

Experiences with Systems	Availability of Resources	Availability of Opportunities
-Negative Attitudes (Family 1, 2, 3, 4, & 5)	-Lack of Time (Family 1, 2, 3, & 4)	-Limited Employment Opportunities (Family 1, 3, 4, & 5)
-Low Expectations (Family 1, 2, 3, 4, & 5)	-Lack of Money (Family 1, 2, & 5)	-Limited Post-Secondary Education Opportunities (Family 3 & 5)
-System Bureaucracy (Family 1, 2, 3, 4 & 5)	-Lack of Knowledge (Family 1, 2, 3, & 5)	-Limited Independent/Supported Living Opportunities (Family 1, 2, 3, & 5)
-Inadequate Services (Family 1, 2, 3, 4, & 5)	-Lack of Support (Family 1, 2, 3, 4, & 5)	-Limited Recreational/Social Activities Opportunities (Family 1, 2, 3, 4, & 5)

Context

The next component of the paradigm model of grounded theory is context or contextual conditions (see Figure 1). Context has been defined as “the specific set of properties that pertain to a phenomenon” (Strauss & Corbin, 1990, p. 96). In this study, the context was the specific set of properties that were in place when parents were in the process of developing a vision for their child’s future life. For many families in this process, planning for the future lives of their children with significant disabilities was driven by the services their children received through the school system (i.e., transitional services). At the same time, contextual conditions were also, “the specific set of conditions (patterns of conditions) that intersect dimensionally at this time and place to

create the set of circumstances or problems to which persons respond through actions/interactions” (Strauss & Corbin, 1998, p. 132).

Often times, issues between school personnel and families can develop during this period of time because of differing expectations for the services the children are receiving in school as well as differing definitions of the children’s future lives. Certain circumstances or problems can also develop within the family unit itself, independent from the school or its services. Both of these can cause families to take certain actions and not others, and to interact both within and outside the family unit in particular ways. The contextual conditions identified in this theoretical model are: levels of collaboration, violations of individualized programming, failure to acknowledge wishes of family members, and ongoing family issues.

Levels of Collaboration

The first of the contextual conditions of this theoretical model was levels of collaboration. This condition focused on the collaborative relationships between school personnel and parents of the children with significant disabilities who participated in the study. It has been said that a successful collaborative relationship between schools and families is one of the most important predictors in whether or not students with disabilities are successful in school as well as in their transition out of the school system (Blackorby et al., 2007; Carter, 2002; Mueller, 2004; Nowell & Salem, 2007; Schrag & Schrag, 2004). Three different dimensions influenced the collaborative relationship between the participants and their child’s school personnel: school practices that do not lead to parental involvement, school practices that lead to parental involvement, and attitudes of school personnel.

Practices Discouraging Parental Involvement. Participants identified a number of notable school practices that were barriers to their involvement in the process of planning for the future lives of their children. These practices ranged from the structure of IEP meetings, the interactions between school staff and the parents, the perceived attitude of their children's special education teachers and other service providers, and actions taken by the school that caused negative reactions within the parents. All of these practices had an effect on the way that these parents viewed and defined their relationships with school personnel who were providing services to their children with significant disabilities and who were helping to plan their children's future lives. Because of these practices, parents took specific actions or interactions in order to manage, handle, and/or respond to these barriers and to carry out their own vision of the future life of their child.

Feelings of Intimidation. The first school practice identified as being a barrier to their collaborative involvement with school personnel was the use of special education jargon and words or concepts not understood by parents. Latoya, Jamar's mom, shared:

It's very intimidating. I think for parents, especially early on, they don't have any clue. And they don't have the dictionary to say, "Antecedents? What are they talking about? What happened before?" Well, I can think of a lot of things that happened before this behavioral episode that resulted in this huge meeting. I think, going in, it was almost like a crash course. Um, on the job training. All about IEPs and behavior. And what does this mean? And what does that mean? It's hard to participate. It's really hard to participate.

Latoya also said she felt intimidated when the school did not allow her advocate to participate in the meeting. When asked if she felt intimidated at times, she explained, "Oh, definitely. And even when I had resources with me to help me advocate for him. Oh,

man. They'd shut that down in a hurry. 'Well, you're not really part of the IEP team.'

It's like, 'Yes, they are.'"

Likewise, Karina, C  zar's mom, also shared that she felt intimidated by the school. One of her biggest concerns was the fact that her son had behavior problems and she was scared that the school would refuse to provide him services because of these.

When asked if there were times when she felt intimidated by the school, she responded:

Of course behind the scenes, yes, because I know if they don't treat him right he can become aggressive. At any point I can't say, "Oh no my son is [an] angel." But yeah we always have the fear you know, whatever we do it is going to fall apart because [the school] can't do anything for you, they don't want to listen, they don't want to do anything.

Maria, Esperanza's mom, also reported feeling intimidated by the school. When asked if there were times that she felt intimidated by the school, she stated:

Oh yeah. That is why we had lawyers. I've been through a lot. I mean I've been pushed, I've been called names. I remember being in an IEP meeting where the principal they wouldn't even talk to me. He would talk to everybody else but me. They have done that to me a lot. They will ask somebody else and not really directly ask me. And that is the part I get frustrated with. I am her mom. I mean I do know her best. I don't know the next kid but I do know her.

Feelings of Discomfort/Embarrassment. The next school practice identified by participants as being a barrier to their collaborative involvement was school personnel talking about their children in negative ways which caused them to feel uncomfortable.

For example, Maria shared:

The thing that made me feel real uncomfortable is when they would talk about [Esperanza] in a negative way. It was always in a negative way. The other thing that really made me feel uncomfortable was they would all come prepared on like how to work with me and I heard them talking about that I am a difficult mom. And I am not. I am not a difficult mom. I would just say, "No." or "I'm not signing that." Or I would bring in someone to help me. You know I'm like wow. They already come into this meeting negative. They already have their goal and their agenda and that is it.

Latoya, Jamar's mom, also admitted to having similar experiences with professionals from her son's school. She explained:

You know, the only good thing they could say about him is, "well, he's really cute." And it's like, you know, "oh, and that's the positive. Now let's get on to this other stuff." I had some really bad IEP's. I've had an IEP where it was me, and I think I counted thirteen people around the table, when I wanted him to ride the regular school bus to school

Rosa, Celina's mom, also described feelings of embarrassment when she had to go to meetings about her daughter's behavior at school. She stated:

There have been a few times when, you know, I have been very glad that [my husband] has been there because as empowered as I can be, sometimes when it's your own son or daughter, you melt. And I have shed a few tears and have come away feeling very embarrassed. Especially, with [Celina], she's my problem child but they pissed me off a lot with [her]. They just didn't see the true [Celina] and when she had those behaviors you know, it was negative.

Maria, Esperanza's mom, also felt like the school personnel blamed her for her daughter's behavior. She explained:

It's always the parents' fault. "This kid is behaving this way because the parents let them do what they want." Granted some parents do but they don't realize that we as parents don't intentionally try to get our kid to act this way. We do things sometimes to divert certain things not realizing that we are creating other things. You know, you try to survive and make it through the day and I would do what I needed to do to make it through the day with her.

Not Feeling like an Equal Member. Another school practice identified as being a barrier to their collaborative involvement with school personnel was not being treated like an equal member of the IEP team. When asked if she felt like an equal member of her son's IEP team, Latoya stated:

I know I wasn't before, of course, I'm an attorney now and doing work for the [state] Department of Education and so the staff that are working with me are aware of that. So, "Oh, she's an equal member now." Five years ago, was that the case? No. I mean, they've even said this in meetings, "there can always be a dissenter in our IEP team." It's like, "oh, great. I'm always the dissenter." Well, they'd say, "well, we think that this is not the appropriate placement." "This is

the decision of the IEP team.” And I’d say, and my advocate would be there, and somebody else working with [Jamar] outside of the school would be there. We’d all say, “Well, you know, having him in an inclusive setting, he gets this benefit, this benefit, this benefit, this benefit. Well, there can always be dissenters in the meeting.” And they’d tell my resources, “Well, you are not part of this IEP team.” “And we don’t have to take into consideration, what you are saying.” So yeah, that’s my impression of my role on the IEP team. “You’re the dissenter.”

Rosa, Celina’s mom, also expressed her feelings of not feeling like an equal member of her daughter’s IEP team. She recalled:

Of course we didn’t feel like equal partners. When they pulled her out of the regular setting, um, certainly I didn’t feel those were equal decisions. There were a whole lot of undercurrents to that whole situation. That set the whole thing up for failure in the first place. This teacher had been gone on leave and for a whole year and when she came back [Celina] was in her class and nobody asked her if she wanted her. And I think she came back pissed that because she was gone, she got [Celina]. I just feel that that was the attitude and the fact that they wouldn’t move her out of that class into another class made me feel that that’s exactly what they did. They put her into somebody’s class that didn’t have a say. By and large we have felt like equal partners. By and large we felt that we had to maybe exert ourselves more than we would have liked to, to be that equal partner.

Karina, César’s mom, also describes her feelings of not being an equal partner with the school system when it came to the services her son was receiving. She stated, *“Of course like any other service they try to get away with things. I think it depends on the parents. I think in any place if you let them, they will go as far as they can.”*

This also included parents feeling like school personnel disregarded what they said in IEP meetings. For example, Maria shared, *“I would say, this is what works at home, and they would do the opposite. They would do the total opposite and it would be like in one ear and out the other.”* Rosa, Celina’s mom, also felt like the school disregarded what she wanted for her daughter. She recalled:

One of the things I do tell the school is that I really would like them to work on social skills because she’s not going to be dealing with any academics, really. She’s not going to, you know, have to take any academics. I ask the school to keep their eye out for any other students at the school, that would take an interest in

her, that would maybe want to go out to lunch with her because seniors can leave for lunch. [Celina] has never left for lunch because nobody's ever invited her. Now whether they will or not? I've asked them to do things like that before. It's always like, "Oh, yeah. Yeah, that's a great idea." But they never do.

Not Feeling Respected. Another school practice identified as being a barrier to their collaborative involvement with school personnel was not being treated with respect by school personnel. This included the parents' feeling like school personnel did not respect the vision they had for their children's future or telling the parents that their expectations for their children's future were not realistic. Nina, Koda's mom, said she didn't feel like her son's teacher respected her wishes. She stated:

Well like I said I had asked his teacher to send him homework home every night and that didn't happen. I had asked his teacher to work on social skills and that didn't happen. So I think when it is convenient for them, when it is an easy goal for them then they will follow through with it but when it comes to something that I feel my son needs because I have gone through it, I don't feel like they respect my wishes for him.

Latoya, Jamar's mom, also felt like the school system did not show respect to parents whose children were receiving special education services. Because of her current job she was able to talk with many other parents who have children with disabilities and her experiences with the school system were similar. She explained:

I'm sure a lot of parents that walk into these meetings do not get any degree of respect or any degree of um, "we want to cooperate with you." I've had one parent relate to me that her husband was told by the teacher, and this was a family from out of the country, um, she was told, "I am the alpha female in this group." And her husband was so offended. There's an issue there about the culture but there is also an issue of [sarcastically] "Boy, that really breeds the collaboration that you need in the IEP." So I not only hear the stories, I've experienced it. And I know it's still going on.

She also felt that the school personnel did not respect the goals and expectations that she has for her son's future life. She felt like the school saw her expectations as being too high. She shared:

I get that sense. That the school is saying, "Well, you can keep having those dreams and aspirations," but, I think they may be dismissed out of hand or politely listened to and then, "but we're going to do it this way." I think they respect me as an individual but I think they're going to be thinking things like, "Boy, she's not being realistic." I have certainly gotten that before. "You're not being realistic to have him participate in this or that." So, no, I don't think that's respected at all.

Similarly, Karina, C  zar's mom, felt the school district did not listen to what she had to say about dealing with her son's behavior because she was the parent. Thus, she did not feel like she was shown respect by school personnel. She explained:

That's another thing, the teachers fill our file with something that maybe was true or not I don't know but they pushed him to react because they always put him in a timeout chair. I don't know how they treat the kids right now but at that time they always put him in timeout and you know they put pressure on him and it was worse instead of calming him down it was worse. We kept telling them, "if you talk to him, if you do this" and they would keep saying, "oh yeah" because I'm the parent. "But you don't have the same thing in the home environment." But I keep telling them, "he is coming from a school environment and they never had any problems." Of course like I say, they have a few things here and there but nothing that oh he is going to be kicked out of the school.

Negative/Inconvenient IEP Meetings. Another school practice identified as being a barrier to their collaborative relationship with school staff was negative or inconvenient IEP meetings. This included school staff not scheduling the child's IEP meeting at a convenient time for the parents. For example, Latoya, Jamar's mom, explained:

Rarely do they ask me what day would be best. They give me the date and time and the place and then they say, "If you have any problems with this let us know." So I know my rights. I know that if I didn't want it there I didn't have to. If I wanted a different day or time but I'll tell you, they make it very clear that they only have these times.

Rosa, Celina's mom, who worked as a family advocate for a state department of education for several years, also felt like the school districts did not take into account the families' schedules when setting up IEP meetings for their children. She shared:

I have supported plenty of families who have never been given the option of when their IEP is scheduled and when they ask they were told, "Sorry, we can't leave the school grounds." Or "We only have these times. These are our IEP times." I have supported plenty of families and I know that it's not always done that way. With me it's done right because they have to because they know I know.

Along with scheduling IEP meetings that are not convenient for parents, the negative tone that often accompanies IEP meetings was something mentioned as a barrier to their participation. For example, Maria described negative IEP meetings she has experienced. She shared:

I had a negative [IEP meeting] this last time. They've been pretty negative for years and then we did pretty good and now that there are new people, this last meeting it went alright but the therapist kind of upset me and said that everybody thinks [Esperanza] is getting favoritism. It kind of upset me because she said that in the meeting and she doesn't even know her.

Latoya, Jamar's mom, also feels like sometimes there is a negative tone in her son's IEP meetings that affects the relationship she has with school staff. She explained:

I wonder though, how you set the tone. I don't know that some of the educators that I've worked with realize the tone they're setting for the meeting and how some of the things they say can really rub you the wrong way. I'm sure, they're well meaning and don't get me wrong, like, "Sure, we think he's going to be successful but, you know, lower your expectations." That really bothers me. Sometimes you can sense the tone when you go into the meeting and immediately you know, "oh, this is going to be really bad." And whatever I had written down is probably not even going to get said because I've got a bunch of paperwork. They're just sitting there. Even with their arms crossed. You see the meeting ahead of time and then they let you into the room and that's generally bad.

Rosa, Celina's mom, had also experienced IEP meetings in which not every person that should be at the meeting was invited. She described a situation with her youngest daughter, Marcella. She stated:

So [Marcella] is in middle school. She is supposed to be transitioning over to high school. We had her transition staffing last week. Nobody from [the high school] was invited. The day of the staffing I said, "By the way, who is coming over from [the high school]?" "Well um, uh nobody. You know, the teacher over here, has swimming that she's responsible for." And I said, "Well you should

have told me. We could have changed the meeting to when she could come.” I said, “Somebody from [the high school] should come.” She said, “Well I sent the notice over there but nobody responded.” I called over to [the high school] and I said, “[Marcella] is having a staffing today. Who from the program is coming over?” They responded to me that they had never got anything from [the middle school] but they would send somebody. They sent the psychologist that actually ended up being a great person to have. She is a young woman and she was great. Anyway, they pulled that on a parent who knows! Imagine what they do to parents who don’t know. Most of them don’t know. Most of them don’t want to know, most of them don’t care. I shouldn’t say they don’t care. They care about their child they just don’t care about all the other crap. Imagine.

Along with inconvenient and negative IEP meetings, the very structure of the IEP documents caused parents to shy away from becoming involved in the educational or transition planning processes of their child. Latoya, Jamar’s mom, stated:

The length of IEPs is ridiculous. I don’t like how long they are. I don’t want a discreet goal in every domain. You know, pick maybe three, maybe four and work towards that. You know, a lot of it, I think, could be addressed just through curriculum modification as long as he’s continuing to learn. The IEPs are not useful. Also, they have always, always, always had a draft IEP prepared in advance and if they are going to do that, I don’t mind because I know that a forty-five minute meeting is a forty-five minute meeting but if they would give me the draft in advance I could say, “this is what I think of this.” “We’ve worked on this goal long enough. Can we just drop this goal and work on something that’s more important at this point?” There has got to be a better way.

Teacher Turnover. The final school practice identified as being a barrier to their collaborative relationship with school staff was teacher turnover. For example, Maria, Esperanza’s mom, explained how this affected her relationship with her daughter’s teacher. She explained:

[The special education teacher and the special education director] knew me, they knew what I wanted, I knew what was expected and actually we really formed a great working relationship and we respected one another so we did really well. Now that they are both gone, like I said there is always turnover, it is like starting that again. We get into those meetings and it can get really frustrated but starting all over again that is the hardest part. She’s been through so many different teachers. She has been through twenty different aides. That is [the] frustrating thing for me and I think for any parent who has a child or adult with a disability.

The turnover is so high that sometimes the people have no clue what they are doing and you have to tell them what their job is

Practices Encouraging Parental Involvement. Participants also identified some school practices that fostered their involvement in the process of planning for the future lives of their children. These practices ranged from the school staff acting like they want to work with their children, school staff asking for the parent's opinion, school staff and parents having a shared vision of the child's future life, opportunities for parents to participate in on-going training, having their child with the disability attend their own IEP meeting, and school staff focusing IEP meetings on the positive. All of these practices had an impact on the way these parents viewed and defined their relationship with school personnel who were providing services to their children with significant disabilities and who were helping to plan their children's future lives.

Wanting to Work with My Child. The first school practice identified by parents as helping to build their collaborative relationship with school staff was when the staff acted like they wanted to work with their child. For example, Karina, César's mom, describes how this practice made her feel toward the staff providing services to her son. She explained:

Having the feeling that people actually want, you know, [César's] success. People that, you know, work with us for success and I say, "You can see it" and they say, "Oh yes because I know he can do it. I know we can work on this. I know [César] has the ability to accomplish this and that." So that was the things that I think oh yes we can work together and we can accomplish those goals.

Child Attending the IEP Meeting. Another school practice identified by participants as impacting their collaborative relationship with school personnel was when their children were able to attend their own IEP meeting. Rosa, Celina's mom, talks about

how important she feels it is to have her daughters attend her own IEP meetings. She shared:

The girls have always been at their IEP meetings since about um, [Marcella] has always been. So [Celina], we probably didn't take her to her first few IEP meetings but what we found was that the minute we brought her it took a different focus. People tended not to be quite so negative with them there, even when they were little and couldn't really speak up for themselves. But no the girls, I've always insisted that the girls be present because I think it's, especially since I learned what a lot of people with disabilities have to say and that's nothing about me without me. And that always stuck so true with me that I have just always suggested to parents, bring your kids. Bring them. Have them there, babies, you know, first graders. Yeah they might get a little bit out of control, you know, but give them some crayons and have them there because they shouldn't, nothing about them without them. And the earlier you start that, the better it is going to be because there has been too many times I think I saw it happen in [the segregated school where I worked] a lot where decisions were made without the individual there and that is just not right. It's not respectful and I don't care how completely disabled they are, if you are going to talk about them they should be there.

Nina, Koda's mom, also feels like having her son at his own IEP meeting is a positive experience. She explained:

It is a positive experience I think because I think he needs to participate in goals and conversations about himself. He usually doesn't participate but at least he is listening. All we ever usually get out of him is "I don't know" but at least he is listening to the goals that we are setting for him and either he can agree or disagree at that point.

Having a Shared Vision. The next school practice discussed by parents as being helpful in fostering their involvement with school personnel was when school personnel shared their vision for their children's future lives. For example, when Latoya, Jamar's mom, was asked what helped her to have a good working relationship with school staff, she responded, "*Having a shared vision with everyone who is involved in his life.*"

Feeling Included in the Process. The next school practice identified by parents as helping to foster their collaborative relationship with school personnel was when school

staff included them in the process. For example, Karina, C  zar’s mom, explains how this practice made her feel toward the staff providing services to her son. She explained:

My relationship with [school staff] was very close, you know. The case manager, she is still watching [C  zar] once in awhile when I call her when I need it. She always say, “What do you think? Do you think it would be good idea to invite this person and this person?” And I say, “Oh yeah.” And she say, “Okay I just let you know so you can do whatever you want.” So yeah they always tell me you know who is coming and why so it was never a surprise. Probably because it was here [at our house] it was easier for them to let me know who was coming.

IEP Meetings Focusing on the Positive. Another school practice that parents described as being helpful in building collaborative relationships with school staff was when IEP meetings focused on the positive things about their children. For example, Rosa, Celina’s mom, described how she insisted on having school staff focus on the things her daughter was able to do, not on what she couldn’t do. She shared:

I have attended many a staff meeting where the parents were all you do is hear the bad, you know, I’m sitting there supporting the mom who usually can’t speak English and you know out of the clear blue I will say, “You know what, I think she knows all of this stuff. She probably knows it better than you do. Can you tell her anything positive about what is going on in the classroom?” It changes the whole focus. It’s like they go, “Oh we have permission to do that. Wow!” We made it known from the beginning that we know where all the weaknesses are. We want to hear about the strengths. So it has really taken the focus off what they can do and I think it has really helped us develop the IEP more around what their strengths are. The goals still revolve around improving what they can’t do but there is just a whole different tone now since [my husband] and I have been very adamant that nobody knows her weaknesses better than we do but what are her strengths. So I have not attended an IEP meeting in probably the last five years where they don’t start out with “She is doing really well. This is what we really see her just really shining in.” It just kind of changed the tone of it. So we are there of course to develop an IEP with goals around what is going to help them do what they can’t do better but we just always felt it was important to set a tone of this is a human being and they do have some strengths so let’s hear what those are and then we can move on to developing goals around what they can’t do but I think that’s because we have taken charge of that.

This had the effect of reducing some of the negative language that repeatedly occurs frequently in such meetings.

Ongoing Training for Parents. The next school practice that parents described as helping to build a collaborative relationship with school staff was ongoing training for parents. For most parents with children who have disabilities, they are entering the field of special education with no knowledge. Because of this they can feel intimidated by the structure, law, and processes of special education. One way that parents can overcome these feelings of intimidation is to gain more knowledge in this area. For example, Latoya, Jamar's mom, feels like ongoing training for parents would help parents to be more involved in the education and transition planning processes for their children. She explained:

I think to make things comfortable you'd almost have to have an ongoing series of trainings for parents, where they were learning all about, "This is what an IEP is" and kind of how it relates to what you've got right now and this is an IFSP and when you get into these meetings, they're going to talk about all this stuff. That would be helpful.

School Personnel Attitudes. The final dimension influencing the collaborative relationship between the participants and their children's service providers was school personnel attitudes. These attitudes had a huge impact on whether or not parents felt comfortable participating with school personnel to prepare and plan for their children's future lives. Often, as reported by participants, school personnel attitudes created barriers to parental involvement in the process of planning for the future lives of their children. These attitudes also had an affect on the way these parents viewed and defined their relationship with school personnel who were providing services to their children with significant disabilities and who were helping to plan their children's future lives. Because of these attitudes, parents took specific actions or interactions in order to manage, handle,

and/or respond to these barriers and to carry out their own vision of the future lives of their children.

Maria, Esperanza's mom, explained how school personnel attitudes affected the view of her relationship with her daughter's service providers. She shared:

I remember when [Esperanza] was being kicked out [of school] because of her behaviors and the special educator refused to teach her and people would come in and be afraid of her. They are like, "No I'm not going to do it. I refuse to do it. No I don't want to be around her. She is too aggressive. She is this. She is too this." I had one person tell me, "she's a child only a mother can love." I guess the last straw was this therapist, she was pregnant and I understand where she was coming from but it was really upsetting when she said, "I really don't want to work with [Esperanza] because I'm pregnant and I don't know what is going to happen." I'm like, "You think my kid is going to hurt your baby or give your baby a disease?" I think she was afraid if [Esperanza] hit her. I mean I understood that but she wouldn't do that if you didn't approach her that way.

Karina, César's mom, also experienced attitudinal barriers when working with her son's service providers. She described:

It depends on [who] you work with because even in [the old school district] there was one lady who didn't do much and it was just me and I talked with the superintendent. The only thing that the school keep telling me is, "Oh yeah we understand your son's services. I understand your son needs this. I understand that he needs services." She understands everything but she was not doing anything. So you know when we went to [the school district] they told me up in my face, "No we don't want to work with you." So it was the same.

Other participants also described attitudinal barriers that have had an effect on their ability or desire to work collaboratively with school personnel. Latoya, Jamar's mom, shared, "A lot of teachers that I have worked always tell me, 'I've been teaching Special Education for twenty-five years.' And I always think, 'And that means you are really set in your ways.'" Likewise, Rosa, Celina's mom, has experienced several attitudinal barriers to her collaborative relationship with staff members at her daughter's school. She explained:

[The Challenge Program] was so much better than fighting the wall that we had hit with this teacher who had absolutely no desire to teach [Celina]. She didn't know why [Celina] was in her class, she didn't go to school for this, and "those kids" have their own program. They shouldn't be in the regular classroom and I just couldn't deal with that. I don't want her in a classroom where there is a teacher like that one we had before but on the other hand, if [Celina] shows an interest in something like Spanish, it shouldn't totally hinge on the teacher being accepting. It's her right. She has a right to be in that classroom. But the special ed. people tip toe and I've always felt this, as long as I have been involved with the Challenge Program, they don't feel part of the school. If you had a good teacher in there, I can envision it now. I had always been able to envision the challenge programs not being that bad. But I have yet to find one of them in my experience, and we dealt with elementary, middle school and high school, I have not found a teacher yet that could be that wonderful teacher that would say, "Hey, this is just a place to come and drop off your backpack and get your assignments for the day and then you go out and you go to math and you go here and you go there. And I'll send my paras and they will go check on you or they will go with you for the first month and then after that, here's our expectations; you are going to be there." And would go to the rest of the school and say, "these are our kids. Not mine. They're your kids. So you tell me if you see any problems." I have not seen that yet.

Rosa also met with attitudinal barriers towards her daughter during IEP meetings. She explained:

I noticed that they have a hard time talking to [Celina] during her IEP meetings. They'll talk to us whereas we will have more of a tendency to talk to [Celina]. "Is that true? Did you really do that?" It's hard for them. You know it makes you wonder how easy a time they have communicating directly with them anyway if they can't do it in that setting. It's a more intimidating setting; it's a more formal setting. I think maybe we make them a little more uncomfortable too, you know, just having mom and dad there but I've said to [my husband], "Isn't it amazing how we will talk to [Celina] but they won't?"

Violations of Individualized Programming

According to the Individuals with Disabilities Education Act (IDEA), it is mandated that every child who qualifies for special education must receive an individualized education based on their needs as determined by an IEP team. Several participants mentioned that they felt like their children were not receiving services that were necessarily meeting their child's individual needs. For example, Rosa, Celina's

mom, felt the transition process was not always individualized for her daughter. She stated:

Oh they're following the letter of the law but there's no room for individualization. Even in this law, individualization it's more lip service than anything. The most important thing for parents to know is that it should be an individualized process. The other important thing for them to know is that it is not. You just have to fight to get it to be an individualized process. They still have a cookie cutter way of transitioning and that's how they want to do it and, you know, it should be more individualized.

Latoya, Jamar's mom, felt the same about the need for transition services to be individualized. She stated, *"Well I think transitions are always really hard and often times I don't think there is enough attention paid to the transition and how individualized it needs to be."* Maria, Esperanza's mom, also felt like the school did not want to meet the individual needs of her daughter. She described:

Sometimes we'll have disagreements and then sometimes I will feel like I'm trapped. That's the hardest part for me but I do let the school know how I feel. I do let them know that [Esperanza] is entitled to certain things and they know that. But I think a lot of what happens is like a newer teacher or the newer therapist comes in and they decide, "Oh no, this is not fair. [Esperanza] is getting this." It is like you can't compare [Esperanza] to other students. It is like comparing oranges to apples. It's not the same.

In this study, several school practices were identified by participants as not meeting the individual needs of their children. These practices included similar goals for all students in the same program, narrowly focused transition services and post-school outcomes, center-based school programs, and assignments of paraprofessionals to all students with similar disability labels.

Similar Goals for All Children. One practice participants in this study identified as not being individualized was having the same or similar goals for all children in a particular type of program and/or already setting goals for the child's IEP without input

from the parents. Rosa, Celina's mom, experienced this with her daughter's IEP team.

She stated:

Sometimes they'll actually send me drafts of their reports so I can read them before the IEP meeting. A couple of times they even sent me the draft goals and I had to say to them, "Those are supposed to be determined at the meeting. There really shouldn't be any preconceived ideas." Well the district has gone to this new IEP form and you just pull it down, you know, and it was just like whatever and then we talk about them. So, I would say about five years ago I stopped really taking the IEPs real seriously.

Latoya, Jamar's mom, also experienced this same practice with her son's IEP goals. She shared:

I have to tell you things have changed since they have gone to these pull a goal off the computer things. If you suggest something it's like "oh yes I think there is a goal on the computer for that." It is like, "so can you put anything on there that isn't on the computer?" They really have got them into this routine of the computer just shoots everything out.

Similarly, Karina felt that the school sets goals for her son, César that did not take into account their cultural background. She explained:

One of the goals at school was to teach him how to shake hands instead of hug. But I am coming from a different culture, you know, we kiss each other as soon as we see a family member or friend.

Narrowly Focused Transition Services and Post-School Outcomes. Another practice identified by participants as not being individualized was school staff only focusing their transition services on one area of post school life. For example, Latoya, Jamar's mom, felt like the school staff only focused their transition services on employment for her son. She stated, *"I think the other thing is that transitioning encompasses a whole area of things, not just leaving school and getting a job which is what they focus on."* Rosa, Celina's mom, also felt like her daughter's teacher only had

one option for post school living arrangements for all the students in her program. She explained:

The teacher at this school, the main teacher, the head teacher, she's got a daughter with significant disabilities and she's got her in the day program and she never lets you really finish a sentence. She's just one of these people, "I've got my kid over there and that's where all these kids should be."

Center-Based School Programs. The next practice identified by participants as not being individualized was that they were not allowed to enroll their children in any school in the district. Instead, they have set programs in place where they insisted on having these children attend. This left little options for parents to enroll their children in a school where they would be able to go to school with their nondisabled siblings or with the other children from their neighborhoods. Thus, these children are not forming bonds and friendships with those peers that they might have the opportunity to interact with on a daily basis. This was something that Latoya, Jamar's mom, was faced with when deciding where she should enroll her son when he got to high school. She explained:

Both high schools have the same life skills program so either way he would have been in the life skills program. Just because of his level of need. "Oh, his level of need; he's going to go into the life skills program. This is the person you need to talk to." This idea of, "Oh we've got programs at both the schools and no matter what you are going to go into that program." It's really challenging.

Maria, Esperanza's mom, had a similar experience when she tried to enroll her daughter in her neighborhood school after they moved. She shared:

We moved and the day I went to take her to school, I went in and said, "You know what, she is disabled. She has an IEP" and they almost freaked out because the school is one of the highest academic [schools] and all of the kids [with disabilities] that should technically go to that school get bused somewhere else. Well I wouldn't allow that to happen because we just moved here and I wanted [my children] to get to know the neighborhood kids and have neighborhood friends.

Along with the pre-set programs that districts insisted that students with significant disabilities attend, schools also provided similar services to these students just based on their disability label or on their membership in these programs. Maria, Esperanza's mom, felt like the labels her daughter had received over the years had done more harm than good and based on these labels, only certain services had been available.

She explained:

She's had so many labels. So what? She is still who she is. The labels are intended so that you can get stuff which to me is kind of ironic. In order for her to qualify she has to have a specific label. So let's just give her this label in order to get services and it's like I think labels do more harm than the actual disability and so we have fought the system with a lot of labels. I mean one teacher even told me that she was afraid to work with [Esperanza] when she got her file. She said, "I have to honestly tell you when I read this I was like oh my God what am I going to do with this kid in my class?" Like I said, they do more actual harm than good to our kids. I wish that they would provide resources for children like [Esperanza], I mean actual true resources. You know, they say here's this and here's that. Well explain to me how you think this is going to benefit [Esperanza]. Not just because it is a system out there who works with children who are disabled or adults who are disabled but why? You take [Esperanza's] disability and tell me why you think this is going to work for her. Not just because she has got this label but because you know her.

Latoya, Jamar's mom, also explained that because her son is in a program for students with significant disabilities he receives the same instruction and modifications that all the other students in the program receive. She shared:

They have the life skills academic courses which are modifications of required courses for ninth and tenth grade. So you have kids in ninth grade who are taking geography, which would be required in tenth grade. That's not such a big problem. It's when you have a modified program like that, are these modifications based on the child's level of need? Or is there just a straight across modification? The modified courses are just that, one major modification. I don't see a lot of individualized modification. I understand that the caseloads are big. I'll be frank; a lot of classroom teachers do not want children with disabilities in their classes especially ones with more significant needs. Again, I think it's a shame that you can say, "I don't teach those students." That just bothers me to no end.

Assignment of Paraprofessionals. The final practice identified by participants as not being individualized was the assignment of paraprofessionals. Several researchers have studied the use of paraprofessionals and have found that these types of supports are often misused with this population of students. All but one participant in this study discussed the fact that at some point in their child's educational experience they were assigned a paraprofessional for support that ended up being a barrier to their child's independence. Maria, Esperanza's mom, described her daughter's experience with being assigned a one-to-one paraprofessional. She shared:

At the beginning it was okay for [Esperanza] to have the para there and then [Esperanza] started realizing, "I don't want you here with me all the time." [She] would have to sit in the back of the room and it would be [Esperanza] and the para, [Esperanza] and the para, always [Esperanza] and the para and after a while she just got tied of [Esperanza] and the para. Each one of these kids has an adult. The ratio of adults to students is there are more adults than there are students. I don't think she likes them hovering over her. She associated it with adults doing this and that and her not having any control.

Karina, César's mom, also expressed that although her son had a very good relationship with his paraprofessional; he became reliant on her support and would become angry if she worked with any of the other students. She explained:

Their relationship is very good. They have a very good relationship. That's nice. It's nice to see that people want to go with him you know different places. So it was good for us too. But sometimes the activities he can't go because he can't be around any other kids. He was thinking [the para] was at the school for him. She can't do anything with any other kids because he was like, "You are working with me. You can't work with anybody else."

Latoya, Jamar's mom, also experienced similar barriers to her son's progress towards independence and although she requested this type of support be faded from her son's program, the school insisted that it continue. She stated:

The first thing I would do is take away the one-to-one para. I have been trying to get rid of it for a long time. He has really, really become reliant on having

somebody with him all the time and I am really concerned about that. I've talked to other parents who have actually talked to educators who complain about parents who want the one-to-one para. Not everybody wants that. I've asked to start weaning the para away from him. End up not getting implemented because there's not buy-in from the staff. So I could say, "We should let [Jamar] do this independently." And they say, "Sure, we'll put that in the IEP. That's a goal." And then there is every reason in the world that we couldn't meet that goal because he's just not going to be independent. So IEPs have not been good to me.

When asked what kinds of barriers she thought were in place by having the para there all the time, she responded:

Oh, tons of barriers because he can't interact normally with other kids. In fact, his para yesterday, told me this story, because he was in gym class which has typical peers in it. Yesterday afternoon, he sat next to this girl and got arm and arm with her. You know, put his arm through hers and they were elbow to elbow. And she had gym pants on, you know, so he was touching the stripe on her pants and so the para intervened. The girl was comfortable with it. It wasn't like she was having a problem. It was the para saying, you know, "you need to ask if it's okay to touch" and you know, suddenly using that as a teaching moment. But for him, she said, "I think that made him a little tense for the rest of the day." And I'm like, "well, yeah." If I did that to my oldest son and he was talking to a girl he would be mad too. "Hey, stand up straight," that kind of thing. So, that's a barrier. I think there's that reliance. His reliance of, "I can't get up and go to the bathroom, I can't even go to you and ask you if I can go to the bathroom. Somebody's got to come with me when I walk down the hall to go to the bathroom and then they stand outside the door while I'm in there. And if I'm in there too long, they're going to be knocking." "I can't do this on my own. I can't go out to my mom's car on my own." "I can't go into the school on my own." There's always got to be somebody with him. I am thinking that if you put a para one to one with a child, there's always got to be this plan to eventually fade the para from the child's world and I haven't seen that yet. He's got to be able to do things without looking to somebody for a cue all the time. In fact, they finally noticed that he was doing that in his school job. That he was counting out things and he'd look at her and if she was still counting, he'd keep going and so it's one of those things. It's always been an issue of safety. That's what they always tell me. "It's a safety issue, you know. He's been known to run from the school and you know we're concerned." But other high school kids run from the school. I see them all the time. They're walking over to the store and they're not supposed to be just like [Jamar]. There's got to be a better way.

Rosa, Celina's mom, had this same frustrating experience with her daughter's school insisting that she have a one-to-one paraprofessional. She shared:

We were given one-on-one aides for the kids so they could stay in the regular classroom, but the inherent problem with one-on-one aides is what we know happens. You get a one-on-one aide and you have one for the rest of your life. We have made them dependent on paras. [Celina] is in a situation right now that I am so angry about. She had never really had the opportunity to be totally independent in school. [Celina] has had a para on her shoulder all four years. Even when I have insisted that we pull the para. What happens is they pull the para one day, she fucks up and then they put the para back on her because it's too dangerous. It's, "she didn't go where she was supposed to." Who learns from their mistakes the first day? I have said that to them, "Who learns from their mistake the first day? We have got to keep giving her a chance." But they have always had a para with her because they just refuse to take risks over there and I don't see it as much in the regular setting as I see it in the special ed. setting. It's the special ed. people; they are huge barriers to these kids leaving school with a sense of responsibility because they won't let them. They won't let them and they set them up to fail and then they fail and the aid comes back in and that's just the way it is. I've harped on them about it over and over again but they have a lot of control. Anytime you talk about my class, my kids, my this, my that, that's exactly how the school's going to view "you and your kids" and your class and sending them with an aide for every single thing they do just makes them even more owned property by the Special Ed program. It's been disappointing to say the least that they have not been willing to take the risk to help her be as independent as she can be. It has just been easier for them to have someone with her all the time. That makes it difficult once she gets out into the real world and really has to practice being independent. She's just not used to that. She's so used to having somebody there to watch her every move that she really can't think for herself.

Failure to Acknowledge Wishes of Family Members

The next condition making up the context of this theoretical model was failure to acknowledge wishes of family members. This condition focused on transition services currently being provided to the children of these participants through their school districts. As discussed in Chapters I and II, transition services are a set of services developed to assist in the movement of children with disabilities out of the school system and into adulthood. Such services ensure that children are receiving in school the supports needed for them to experience successful post-school outcomes consistent with a higher quality of life.

However, for these services to be effective in the long run, they must not be in conflict with family needs and wishes. Such conflicts were associated with the following contextual conditions: discrepancies between parental expectations of services and the actual services the children were receiving, IEP goals based on school expectations, and post-school plans for their children's future lives based on traditional options.

Discrepancies between Expectations and Services Received. The first dimension of this contextual condition was discrepancies between expectations parents had for their children's services and the actual services their children were receiving. All participants reported that at least some of the services their children received from the school did not meet their expectations. Based on these discrepancies in service expectations, parental wishes were often not taken into account and thus, participants took specific actions/interactions in order to incorporate their own expectations.

As stated in Chapter IV, because of Esperanza's behavioral and medical issues eventually the school was not able to find anyone willing to provide her services. Maria shared:

When we moved out here and they couldn't find anybody to work with [Esperanza] that's when [the special education director] asked me if I was willing to work with her. Finally she told me if I would be willing to do that they would pay me and at first my response was no because [Esperanza] needed to be separate from me but it got to the point where they said they couldn't find anybody to educate her so they wanted to do an out of school placement and send her to a facility. Well that wasn't going to happen. So I finally just said I would do it and that is why I went back to school.

The school district hired Maria as her daughter's primary service provider.

Esperanza is in her final year of public school, although Maria continues to provide all of her services at home. Maria works with Esperanza to increase her independence when it comes to daily living skills by trying to find things for her to do at home. Because of this

service delivery model, a major concern was Esperanza's dependency on her mom. Maria would like for Esperanza to learn to tolerate care from other people. She explained:

We are trying to get other people to do stuff with her. She will go with her brother because she knows her brother. She will go with her father. She'll go with me. She will go with her grandma but we tried to get other people to come in and she just would not open up to them. She doesn't trust them.

Maria expressed the fact that she felt trapped in this situation and felt like she let the school off the hook. She would rather see the school educate her daughter the way that they should so that she can have a life and work to support Esperanza the right way.

Also, as discussed in Chapter IV, C  zar was moved to the transition program early, after years of fighting to get him back into a school-based program. His parents agreed to this arrangement because they wanted their son to receive an education and because having him at home placed a huge financial burden on their family. Karina stated:

The school said, "You know, we were talking about it and we can move [C  zar] to the transition program sooner." Even though you know he wasn't the age, he wasn't ready for that, they said yes and that is when we came up with the transition program.

She felt like they wanted to work with him there, and she felt like they were willing to work with her as well. She felt like even though they were not really accomplishing much with him through the transition program, it was enough for her to see that they were happy to work with her son. She shared, *"It was nice to see how every single person was willing to work with me and you could tell they were proud of themselves on what they accomplish and those little things were enough for me."*

César was preparing to transition out of the school system very soon. For the last few months he had been sharing time between the school's transition program and a community program. Karina shared:

The school has a cooking class. They go to the grocery store and then do the cooking class. Sometimes they go back to the building and help over there. They ride the light rail and go downtown to the mall and walk around. He also works at different jobs.

He attended the community program two days a week. While he was there he participated in a variety of activities and outings. She explained, “*He goes in a group. They go out for dinner or you know they go bowling, hiking, or to the pool. I’m expecting those kinds of things for my boy.*” He did really well with this group and his family would like for him to be able to go more than two days a week. However, this was not something that the school was willing to provide.

Also discussed in Chapter IV, Jamar had been receiving transition services including instruction in academics, daily living skills, communication skills, behavioral supports, adaptive P.E., and support for him to attend non-academic general education classes. Jamar also received a full-time one-on-one paraprofessional who supervised him at all times. This was a support that Latoya would like to see faded from her son's program. She stated:

The para-educators are still there with him and the teacher is still there with him and how are we going to do this so that he stops relying on people? He is looking at them for cues. It wasn't what it was supposed to look like. I can tell you that much. I guess I'm kind of disappointed with the way inclusion is perceived by some schools which is you get a para and you let them sit in a classroom. Often times it is totally different curriculum then the rest of the students because nobody is going to go in and modify the curriculum. It just makes me cringe and I think if inclusion is done well it can be very successful. It is not done well for him.

The district's employment team was providing support for Jamar to participate in work experiences with the assistance of a job coach, although Latoya felt like the options for employment that they had in their program was not the best. She explained:

I believe that they have job coaches that go out with students and work with them. The proposals that I've heard so far as to possible jobs, they're not so good. It's been, you know, go to the nursing home and do the recycling. So I'm not seeing a lot of variety in jobs.

Latoya knows that her son really enjoys peer interactions and would love for her son to be involved in more activities or classes at school where he might be able to engage with typical peers. She shared:

I had a gym teacher, who noticed how well he runs because [Jamar] runs really fast, who said, "Track would be a great thing for him as long as you are there and somebody is there to supervise him." I'm thinking we want an opportunity for having some more peer interaction. Not just peers with disabilities but all kinds of peers.

This was something that Latoya would be very happy for Jamar to participate in, however, he would need a one-on-one support person to be with him and she would not be able to do it because of her work.

Jamar also participated in some activities provided by the local community center board that provide students with disabilities the opportunities to engage in more recreational activities and he also participated in an after school program that focused on social skills development, although there had been comments made that Jamar might be too disabled to participate in this group. Latoya described:

The outside activities that I see for him, particularly offered through the CCB, which is supposed to be providing supports and activities for individuals with disabilities tends to segregate it by the degree of disability and I don't like that internal segregation. He was in a social skills group last year. It was rather frustrating for me because here is a social skills group and it's all for children with special needs, to help them work on their social skills and because of his level of need or his activity level, they were telling me, "maybe this group is not

for him.” And I’m thinking, “It’s a group for kids with special needs. Are you telling me he’s too disabled to take part in this group for children with disabilities?” That was rather frustrating and I understand it was the introduction and suddenly he’s you know, he’d jump up and run out of the room and checking to see if I was still out in the lobby and I understood that but the tolerance wasn’t there. So if you are compliant or unquestioning we are able to teach you but if you are like, “well wait a minute. I need to see what’s going on out here. I need my security factor.” That was really hard to work with.

Again, as stated in Chapter IV, Celina was currently completing her senior year of high school. Unlike other students in the Challenge Program, Celina participated in general education classes for the majority of her day accompanied by her paraprofessional, which Rosa felt was getting in the way of her achieving independence within the school environment. Just a few weeks later, Celina would be walking through the graduation ceremony. Typically once a student in the challenge program has gone through graduation they no longer go to the high school but are moved over into the school district’s transition program for students who are 18 to 21 years of age. Rosa did not want this for Celina. She shared:

She won’t go to the transition program. It’s a place and they go there till they are twenty-one and they take them out, one or two days are a social outing, bowling, movies. Another day might just be there, where they play games and do whatever and talk about, you know, hygiene and the other two days, if you’re lucky, it’s a job placement at Walgreen’s. Where somebody goes with them, probably does the work. And [Celina’s] boyfriend, turns twenty one in December, November, somewhere in there, he doesn’t have a job yet. He’s going to leave that program and not have a job. One of [Celina’s] friends that graduated last year is over there and they only gave him three days a week. They didn’t give him five days a week. I want to steer clear of the transition programs if I possibly can because I have not heard anything good about it. I happen to know a paraprofessional that works at the program. She, herself, doesn’t have much good to say about it. I won’t have her go there.

Finally, as mentioned in Chapter IV, Koda was about to finish his senior year. At that time, his program focused on functional academics, behavior management, and

communication skills. However, Nina said she didn't feel like he was doing anything beneficial at school. She explained:

When we go in there to visit him in the trailer or whatever, he's just sitting or he's playing on the internet or, you know, looking at a magazine or something like that. He's not doing anything educational. That's why I get so upset with the school.

She felt like the school had totally disregarded their wishes. Nina also felt as if the services Koda had received in school had not prepared him to become a successful adult. She felt like the school had not focused enough on skills he would need once he left the school system. She felt like the school system had reinforced his learned helplessness.

Nina was very concerned that her son was not getting the help he needed through the school system. She took it upon her self to set up services outside of school to get Koda some extra help. She explained:

As soon as I found out that [Koda] had these disabilities, my first step was I got him a counselor and I started taking him every week to talk to this counselor. From there then I started thinking well there has to be some other transition programs or something and I got him put into a program where they teach them how to do laundry, how to measure water for food and things like that. Then from there we got a mentor to be able to take him out and do things because we can't because of all the kids and he needs that individual attention. So then from there we put him into a wilderness program where on the weekends he gets to go camping or go hiking or whatever the case may be.

Although Nina felt like these services were beneficial for Koda, they were only in place for a short period of time.

IEP Goals Based on School Expectations. The next dimension of this contextual condition was IEP goals based on school expectations. All participants described goals that the school was working on with their children that did not necessarily take into consideration their expectations. Again, because of these discrepancies, family expectations were often overlooked.

Esperanza's IEP contained goals related to working on independence, developing skills for daily living, using public transportation with support, and continuing to access her computer programs. Maria admitted that she felt frustrated because although they had a plan in place for Esperanza, there was just not the support from the school to make it successful. She explained, *"We will have really good stuff written down and it looks really good and sounds really good, but then there's not that support."*

César's IEP contained goals related to improving his ability to work, improving his safety out in the community, engaging in social and recreational activities with others, and increased independence. Karina explained, *"He is working in the community, how to cross the street, take the bus, pay his own stuff, and he had a few jobs."* Karina was happy that the school was working with César to be more independent but she did not feel like they could expect much from him. She did not see him being independent or holding a job in the future. She stated, *"We know we can't expect too many things from him."* He was also learning to ride the public transportation system. However, his family did not use public transportation. Karina explained, *"At school he takes the bus or the light rail. At home we go in the car."* César was successfully able to communicate at school using a communication book, hand over hand requests, vocalizations, and gestures. At home, he also used gestures and vocalizations, but did not use any formal communication system such as pictures. At school, César practiced using a fork and spoon when he was eating lunch and snacks. He was somewhat successful with this. However, his teacher had expressed that being fed at home appeared to be inhibiting his independence with this activity. Karina shared, *"Here at home I feed him. They said at school he normally eats himself. But I don't know. Because you know since really that*

was the only time I have interaction with him. I felt comfortable feeding him.” Although C  zar’s family did not always see the importance in the activities he participated in at school, they were very happy that he was able to receive services from the school.

Jamar’s IEP contained goals related to improving his functional skills through activities such as using a calculator, identifying coins and their values, identifying sight words, improving his ability to write short sentences and comprehend written material, and improving his independent skills while at school. However, when Latoya was asked if she felt like the instruction that Jamar was receiving would help him when he got out of school, she responded:

I think, for [Jamar], he’s very interested in a lot of things. He’s interested in animals and maybe it’s helping him to explore that interest. Just to broaden his horizons is one thing. But to help him get further in depth and maybe learn other skills along the way, I don’t see that happening. So, “we did a unit on animals” and that’s what I hear and “we’re doing a unit test.” Which is usually a fill in the blank or multiple choice or something like that. I don’t see something encouraging him to study it more. Maybe the math but he’s pretty proficient with a calculator right now and there’s been no movement towards anything beyond, you know, your basic addition, multiplication, subtraction, division. So I don’t know how much it’s going to help him.

Jamar was also attending a life skills cooking class and participating in unpaid work experiences. Although Latoya would like for her son to have a job once he is out of school, she felt like the school had a limited number of options when it came to providing employment opportunities to her son. She shared:

They do a work experience program. It’s pretty derogatory. It was like a mobile, not supported work, but you know, just bringing the kids with disabilities around to do these really unpalatable jobs in just this mobile unit and that’s kind of what it is. You know, he’s going and he’s taking apart remote controls and I’m thinking, “Okay and how is that engaging to him?” They keep telling me, “He’s such a hard worker.” I know he’s a hard worker but is that something that he really wants to do? Recyclables and that kind of remedial job and if [Jamar] loves to do remedial work, I’m fine with that but if it’s not something he wants to

do I'd like to see someone do an assessment of what he would like to do. I'm not seeing that.

Behavior continued to be a challenge for Jamar, but overall it had improved during the past school year. Latoya wished that the school had done a better job of teaching Jamar to self-regulate his behavior. She shared, *"I think some of the things they do in response to his behavior really probably would have been better to teach him self-regulation but instead it becomes more of a punishment."* Jamar was also working to improve his functional communication and basic language skills in order to access and express information and ideas. Again, Latoya felt as if the push in speech therapy for remedial instruction early on in her son's education should have been replaced with other alternative modes of communication. She explained:

So when he's working on speech therapy it is working on articulation so it's the same as everybody else's. I think I would have been looking at alternative modes of communication at the same time and a little more focus on just giving him the skill to communicate no matter verbally or be it through assistive technology. You know sometimes you have to work around the disability as opposed to trying to fix it.

The main goals for Celina attending general education classes were for her to have the opportunity to observe and interact with her nondisabled peers, learn appropriate social skills, and learn to be more independent. Unfortunately, the paraprofessional continued to go with Celina even after several requests from Rosa that they start to fade the one-on-one supports so the goal of working towards more independence was most likely not going to be met through the school program. She stated:

You know what happens when you have "the program", they belong to the program. They don't belong to the school. It is a sad, sad commentary on our expectations that people with disabilities will go on to lead productive lives in the real world and then we give them bullshit like this in the schools where it is not the real world and they are all part of it's totally out of whack. And we have a glimmer of hope I think ten years ago. And that has now gone by the waste side

because of funding. Because there is not enough money they say. There is not enough paras they say. And yet to me it doesn't take a lot more money and it doesn't really take paras. We have made them dependent on paras.

Also, Rosa had made her wishes known that she did not want Celina participating in community outings provided by the Challenge Program. Rosa stated:

I do not want either of my daughters seen out in the community with a group of kids with disabilities being led around like a herd of cattle. Not because I don't like kids with disabilities but because I feel as if this is a very demeaning and unnatural approach to teaching these kids to function in the outside world.

Koda's current goals and objectives on his IEP focused on spelling and sight word instruction, writing skills, decision making and problem solving skills, controlling his temper, technology skills, math skills focusing on money, and expressing his wants and needs in appropriate ways. He also participated in P.E., art, computer, and woodshop during his years in high school. Nina had been upset about Koda being in woodshop because she said that he gets loaded up on soda and candy and plays on the internet the whole time. His parents asked the school to take him out of this class but he has continued to take it every semester. She shared:

They fought and fought and fought with me about keeping him in woodshop because they said that he says he really enjoys it. Well that is why he enjoyed it. So I mean I fought them but they went ahead and let him go back to woodshop and he wasn't going to tell us.

Once a week, Koda participates in a community outing to the local grocery store to purchase something to eat to practice his money skills. However, Nina does not feel like the school is really preparing her son for the future. She stated:

I asked them if they could concentrate more on street smarts. On things, skills he's going to use when he is in the real world because I didn't feel like he was getting any. He just had that learned helplessness and, "Well, if I keep saying I can't do it enough, then somebody's just going to do it for me." And that's what the school did to him.

Post-School Plans for the Future Based on Traditional Options. The final dimension of this contextual condition was post-school plans for the future lives of these children based on long-established options available to individuals with more severe disabilities. All participants described post-school options presented to them by school staff or options they found on their own that were based on traditional options that have been available to individuals with more significant disabilities throughout the past in our society. Again, because of these limited options, discrepancies between the wishes of the families for their children's future lives and the available opportunities for their post-school lives were not aligned. Thus, families took specific actions and/or interactions in order to incorporate their own expectations for their children's future lives. Despite their efforts, these actions/interactions were not always successful.

As Esperanza transitions into adulthood, supports have been put in place to help her family care for her into the future. Maria explained, *"There is this new adult program well it is not new, it is probably a year old where the family has more control over what happens and so my son and I are going to get involved in that."* Although Maria felt that the post-school options for Esperanza were limited, the post-school supports that were then in place simply provided funding to pay for supports that she will need once school has ended. Because Esperanza would not allow anyone to care for her besides her immediate family, it was likely that no new people would be a part of her life. Maria shared:

I don't want to say she will have no life because she will have a life but I feel bad for her because she has no place to go. I mean she is stuck with just the three or four of us or whoever comes in contact with us. I have a lot of fear of what is going to happen. I feel like we are going to be really isolated.

Karina expressed her fears for the future and feels like there are limited post-school options out there for children like her son, César. She stated, *“It’s hard because there are not too many options unfortunately. We need more options, you know. Options for this kind of kid. Even though all the kids are having special needs, there are kids that need more.”* Of course, they had looked at several different day programs but felt like these did not meet their expectations. Karina shared:

We visit a couple places and I know we can’t expect too much because there is not always state funding but they don’t do much. Let’s put it this way, for us, even though he may not realize, it has to still be clean, you know, a lot of things for them, a lot of options, going out. The couple places that we visit are like an old place that is kind of dirty and they have twenty kids in the same room doing crafts. And that is not what I was expecting for him after school. I don’t see him sitting in a room for eight hours doing crafts, even though for me it would be a relief because I can work and not worry about him. But that is not what I was expecting for him.

For now César continued to participate in the community program two days a week, and the other days he had to go to work with his dad, which was not an appropriate setting, but the family had no other option. César is now on a waiting list for residential services. However, Karina stated that she did not want her son to leave home and that she worried about the time when she would no longer be able to care for him. She explained, *“We are on a waiting list and we are not worried about being on the waiting list. We are not willing to let him go right now and the waiting list will take years and for us that is fine.”*

In two years, Jamar will be a senior in high school. Latoya would like for her son to walk through the graduation ceremony when he is a senior. However, she was concerned about doing this since the school district only provided employment support services after students had gone through graduation. She shared:

I'd like to see him walk through the commencement because he does have a peer group that has been with him since kindergarten. In fact some of them are in his school so I think it would be appropriate for him to at least walk. But my understanding is, there is a choice, you know, if he walks then it is all employment transition type activities from there forth and I would like to see him get more continuing academics.

Latoya had many goals for her son's future once he leaves school. However, she felt as if the school district politely listened to her expectations and then privately disregarded them as being inappropriate and too high. She stated:

I think the expectations are kind of low. "Not full-time work. Oh no probably part-time. Maybe some kind of recreational activity or social program for people with disabilities but maybe not so community based but just a separate group." Those are things that I foresee. I know it's not what I want for him but I just get concerned about the lowered expectations and we'll have to see how this goes. It's like, "Sure, we think he's going to be successful but, you know, lower your expectations." That really bothers me.

Throughout Celina's school years, her parents have been very involved in her educational experience. She stated, *"I'm really looking forward to getting my kids out of high school. Really looking forward to that."* For months, she had been frantically working to put supports in place for her daughters to have a secure, happy, productive adulthood. Celina is currently on the waiting list to receive supported living services through the community center board. She shared:

That would allow us to hire people to do some community participation stuff, to do some personal care, stuff like you know laundry, and that kind of stuff, continue to support her to be able to help her do that at home but you know she's on the waiting list for that. Is not just guaranteed funding when she leaves school she has to be on the waiting list for that. They told me that they thought it would probably be about five years.

Celina will continue to live at home with her parents and two of her sisters. Rosa and her husband have set up a trust fund that will be financed through a large life insurance policy taken out on Rosa. She described:

This house is going to be theirs. As long as they have a house that is theirs, we funded a trust that hopefully will be able to pay for people to come in. But my hope is that they never have to move but that somebody else moves in or out.

After Celina finishes school the goal is that she will be employed at their family business with support from the Department of Vocational Rehabilitation. Rosa shared, *“I want her to be productive. I want her to be doing something meaningful.”*

Koda is eligible to receive services through the school district until he turns 21 years old; however, his parents have decided that he should graduate from high school this year since he is now 18 years old. Although this has been a difficult decision, they felt like this was the best decision for Koda since he has gotten into trouble at school.

Nina explained:

During the IEP meetings, we tried to decide whether we were going to keep him in until twenty-one or go ahead and graduate him. We did go back and forth and we kept changing his IEP because we kept changing our mind. We didn't really discuss, what happens with the services that he's getting from the school after graduation. That was never discussed. I mean, basically, all that we were told was, “once he gets that diploma, he can't come back.”

Koda was enrolled for day services through the community center board. He had also been placed on a waiting list for residential services in a group home or some other type of supported living environment, and he had been linked with the Department of Vocational Rehabilitation to be evaluated for employment services. Although the school district had documented that it had made connections with these adult agencies for Koda, his stepmom did not feel like the school had connected them with any outside services. She reported, *“Nobody told me about any of these services. I just found all this information out on my own and it's because I know how to talk to people and I know that there are services out there.”*

Ongoing Family Issues

Similar to the conditions that focus on the school environment, the final condition making up the context of this theoretical model was ongoing family issues. This contextual condition focused on the structures of the family unit or those things that happened within the family unit, separate from the school system and their services, having an impact on the family as a whole, including the child with the significant disability. These structures, happenings, or events that took place or existed within each of these families can influence the actions or interactions of parents when it comes to envisioning or planning for the future lives of their children. Participants in this study described ongoing family issues that impacted their actions or interactions when planning for the future lives of their children with significant disabilities.

Esperanza's Family Issues. Maria, Esperanza's mom, described three issues that impacted how she viewed and planned for the future life of her daughter. First, the fact that Maria and Esperanza's father were divorced was a huge factor that influenced how she viewed and went about planning for her daughter's future life. Maria and her ex-husband were married for 19 years. They had Esperanza soon after they were married and after years of fighting with the medical system and with the educational system they divorced. The fact that Esperanza's parents were divorced really came into play when Maria was trying to schedule supports for Esperanza. It also played a big part in planning times for respite care, since her family members were the only people Esperanza would tolerate to provide her basic care. Maria described:

We are very close. We still have that closeness. [My ex-husband] lives in [the same town that we do]. He comes over. He sees [Esperanza] every other week Tuesday, Thursday he is there with her and then the other week he is there Tuesday, Thursday, Friday, Saturday, Sunday, so he sees her a lot. When her dad

comes and gets her, he will be here a while and I leave. I'll be gone for like six hours. Six to seven hours on Tuesdays and Thursdays.

Unfortunately, Esperanza refuses to go to her dad's house so her dad has to come to Maria's house to see and provide care to Esperanza. Maria also mentioned that although Esperanza's father does have a say in what happens to her in the future, she has the final say. She shared:

When it comes to decisions with [Esperanza], her dad and I will talk but I have the ultimate say. I make the ultimate decision because he just says, "okay whatever you want to do." He really doesn't disagree. He just pretty much goes by what I say and he says, "I trust whatever you say."

The next issue that influenced Maria's views and planning process for Esperanza's future was the unexpected death of her own father. As previously stated, Esperanza has lived with her mother, her step-father, her maternal grandparents, and her cousin for several years of her life. In fact, her grandparents had lived with her family since soon after Esperanza was born. Maria felt like this was a very difficult event in the life of their family. She explained:

The only thing that has really changed for me was last year when my dad passed like everything just kind of like fell apart. I realized that he was like the rock of us and then when he passed unexpectedly it just kind of devastated us. Of course anybody who loses a family member is devastated. It is not the same.

One of the biggest issues of this experience for their family was the fact that he was very close to Esperanza and was one of the people she would allow to provide her support and care. Thus, her grandpa's death further limited the already limited number of people available to care for Esperanza.

The final issue that really had an impact on Maria's views and planning process for Esperanza's future was the fact that she has another child. Maria's son is getting ready

to graduate from high school and will be going to college soon, but has been very involved in caring and providing support to his sister. Maria described:

Oh [my son] comes everyday right after school at 3 o'clock and then he will stay with her until 7. Mondays, Tuesdays, Wednesdays, and Thursdays and I will go have a break. He feeds her. He knows everything and he will take her for a ride everyday. He'll take her out because she loves to be out. So everyday he will come and he will say, "Are you ready?" She looks forward to him coming. [He] does all of her care. He is an awesome kid. We are fortune. Like I said last time I feel bad because he is young and he has his whole life to live but he was born into this situation and he is use to it. Like he told me, "this is my sister." So I feel okay. I just feel bad because she is a lot of work and sometimes it can be pretty draining and he is so young and you know I don't want him to be put in that situation.

Maria said that her son has expressed his wishes to continue to be actively involved in caring for his sister. He told his mom that if something was to happen to her and she could no longer take care of Esperanza, he wants to take over. She shared:

My son told me, "What do you mean? Where are you going to leave her? You aren't leaving her with nobody. I'm taking her." I said, "No you're not." He says, "Yes I am. Why would you think I wouldn't take my sister?" I said, "You're only 18, son. You have your whole life ahead of you. You know how hard it is with your sister." And he says, "Ma, I don't care. My sister is going to be with me. She's going with me and you need to know that. I told dad. Dad's going to write that down that she going with me." He was really hurt with me. I mean he didn't talk to me for a day because he was so mad at me and I started talking to him and I told him, I said, "[Son], it's not that I don't think that you can take care of her. I think you would be the best person for her but it's a life commitment. You see how my whole life has changed. You see all this stuff we go through. Even when you have her how hard it can be." He's like, "I don't care. And I said, "When you marry somebody or you find somebody and they don't like your sister what are you going to do?" He's like, "I don't know. They can leave." He's that adamant so I talked to him and I said, "Okay [son]. You'll get your sister if that is what you want. I think we are fortunate because he was born into the situation.

So Maria was setting things up so that her son would have shared guardianship. She stated, "So my son is going to be the one who takes guardianship. We both are going to have guardianship. So me and my son and her dad will have guardianship of [Esperanza]."

César's Family Issues. Karina, César's mom, described two issues that have had an influence on how she viewed and planned for the future life of her son. First, the fact that Karina and her husband had other children in the family who are significantly younger than César has been a huge factor when it came to planning for the future life of their son. Karina explained, *"Well it's not only that he's at home. Unfortunately we don't have the time. You know we have to keep living, we have to you know raise our other kids."* Unlike Esperanza's family, they did not have the option of relying on their other children to help provide support to César.

Along with caring for and raising their other children, as well as taking care of César, Karina and her husband must both work outside the family home to make ends meet. Because of this, they don't feel like they have adequate time to provide the kind of life for their son that they would like to provide him. She stated:

We have to work outside the home because otherwise we would be falling into a big hole. And I would like for [César] to have everything, you know, have the time with us, have the time with his sisters, have the time to enjoy his life but, unfortunately we don't have the time because we have to work.

Jamar's Family Issues. Latoya, Jamar's mom, described two issues that have had the most influence on how she viewed and planned for the future life of her son. The first issue was the fact that she has a son who is two years older than Jamar who also has a disability. Because of this, to an extent, she had already had prior experience with the structure of special education, although there have been differences between services provided to her older son who has a mild learning disability and the services provided to Jamar. However, Latoya has admitted that she has felt frustration when dealing with the school for both of her sons. She explained:

Both my children have had IEPs. So my older son has had IEPs and I find them as frustrating as [Jamar's]. Um, just these real low expectations. I have had IEP goals changed between the meeting and the time I get the actual document. No wonder people get really irate about how IEP meetings are going. So when [my older son] started high school and we had our first IEP, and the counselor said, "You know community college is always a fine thing for kids after school." I was like, "Well thanks for having such high expectations." So now it's time for [Jamar] and I'm anticipating this. I can see it coming. For [Jamar], I'm anticipating something like post-school outcomes is going to be work. He is going to work and we are going to put him on the employment teams list and stuff for services and I think that is great. I know he has to work and I know he needs more skills before he is going to be able to but that's not all he is going to do. So, you know, it's that low expectation. And he is probably going to be in the CCD program and that's how we are going to handle it. It is like, "but there's more."

Along with having prior experience with special education, having another son who is just a few years older than Jamar has provided a gauge for Latoya's expectations of Jamar's post school life. She shared:

So they are trying new things like I see it with [my older son] so he is kind of prepping me for this. You know, "I want to try snowboarding. I want to do biking." He jumps bikes and scares the life out of me. "Watch mom!" Um so he's, you know, "I want to be independent. Mom I can ride my bike to go to town. Don't worry about me." He wants to be with his peers and so I think he gains a lot from what his peers are doing so I'm glad he's with the right set of peers. Because they are all going off to college and so it's, "I'm going to go off to college too. There's no doubt in my mind that I am, even though my grades are not so good." I watch that with [Jamar] and I think okay now what's he seeing with the peers that he's with currently? Is it always going to be, "On Monday I go swimming and Tuesday I do art?" I think he also sees what [his older brother] does and I think he would like that same kind of independence and ability to make choices.

The second issue that had a huge impact on how Latoya viewed and planned for her son's post school life is the lack of support she received from extended family and friends. Because their extended family lives so far away there was not an already established support system in place for them to rely on. This caused them to have to rely on outside agencies, which has been difficult for Latoya. She stated, *"I don't see the*

agencies really focusing on the individualized needs of the child. It's more of, 'we support children but it's a one size fits all kind of model.'"

Celina's Family Issues. Rosa, Celina's mom, described three issues that have had an enormous impact on how she has viewed and planned for the future life of her daughter. First, the fact that Celina was adopted has played a huge factor in how Rosa has viewed and planned for her daughter's future life. She shared:

Unlike some of the other families that you'll interview that expected a normal child and didn't get one, we had no expectations because we adopted them that way. I mean we took every one of them fully knowing that they had something. Either Down syndrome or our son was significantly delayed when we got him.

Another issue in Celina's family was that there was more than one child with a disability in their family. Since, Rosa had already gone through the transition process with two of her older children, she admitted that she has done things differently with Celina. She explained:

I didn't know better. I didn't know better back then. I hadn't become a purist yet. I was still being led around by the nose. It was all new to me and I was probably more of a compliant parent than anything. I started seeing the light when we got [Celina] and I had more experience in the arena of disability and so I did things very differently with [my two older children with disabilities] than I did with [Celina] and [Marcella]. I had a lot less headache with [the older two] than I did [Celina] and [Marcella]. I had a lot less headache because again when you don't know you don't know. So you just do whatever they tell you to.

The final ongoing family issue that impacted how Rosa viewed and planned for her daughter's transition out of the school system and into adulthood was the fact that last year she was diagnosed with cancer and was not given long to live. She shared that for the last several months she has been undergoing treatment for her illness and there have been no improvements in her health. Because of this, she admitted that her priorities have

changed with regards to helping her daughter reach her goals for her future life. She explained:

You never want to second guess your kids' dreams. So probably the one dream that she has to move out may not be a dream that gets actualized just because of our situation. In terms of supporting her goals, well you know we love to support them one hundred percent but some goals aren't realistic and some of them are just not possible given our present situation. You know if I didn't have cancer that might be a different story but I think with our situation the way it is most likely she's going to not end up moving out. But I think as far as her goals, I think she has maybe a dream to, she and [her boyfriend] both have said, they want to get married but I think that's more you know kind of a boyfriend/girlfriend kind of thing. I'm not sure there is enough support there for that to happen. Hopefully they will continue seeing each other and enjoying each other's company.

Koda's Family Issues. Nina, Koda's mom, described three issues that have influenced her views and plans for the future life of her son. First, along with taking care of her two biological children and her husband's three children from a previous marriage, she is also currently taking care of her sister's three children. She shared:

Well right now I have full responsibility for my sister's three toddlers. They are four, three and one. I do everything. I am financially responsible. She is not helping us right now with any of the finances or anything. Emotionally I have to be there for them. It is temporary right now but we have a feeling it's going to turn into a full-time thing where we are going to end up taking custody of all three of them and if not all three at least these older two because they are from a different father.

Having eight children to care for, including her son with a significant disability, has been very stressful. So finding somewhere for Koda to go during the day or somewhere for Koda to live outside of the family home when he graduates from high school has become a priority for Nina.

The next issue in Koda's family was the fact that Nina and her husband have had marital problems. This was also a point of stress when planning for the future life of their son, Koda. Nina shared:

[My husband] says I'm a little overbearing. When it comes to the children, that's my responsibility. I get my husband's input but what I say with the children goes. There are different roles for the man and woman in this home.

Unfortunately, sometimes disagreements between them occurred which caused challenges in their marriage. She explained:

We are the exact opposite so we kind of balanced each other out but it's work for us. We have our problems but I think everybody does and when you are mixing this large of a family it gets a little crazy.

The final ongoing issue in Koda's family that influenced how they planned for their son's future was the fact that his dad is an alcoholic. This has been an issue since Koda was a young child. Nina described, *"When his parents divorced, [Koda] went to go live with his dad. His dad was an alcoholic so he usually had [Koda] in the car seat driving around while he was going to the bars and things like that."* Nina feels like one of the reasons her husband drinks is because of Koda's disabilities. She feels like drinking is the way he copes with his only son having a severe disability. She shared:

It was hard because [his dad] drinks. He drinks to forget so he was never aware of what was going on and he didn't realize that it was so severe until I had to sit him down and explain to him, "Look this is not how you are supposed to act. This is not normal." So it was hard for me because I know [my husband] just wanted a boy, as most men wanted a boy to go fishing with and do things like that and [Koda] will never be that.

Summary of Contextual Conditions

In summary, contextual conditions are the specific set of properties that are in place when transition planning was underway between a family and the school. The contextual conditions identified in the theoretical model include: levels of collaboration, violation of individualized programming, failure to acknowledge the wishes of family members, and on-going family issues. Each of these conditions has its own specific dimensions, described in previous sections and shown in Table 5.

Table 5

Contextual Conditions and Associated Dimensions

Levels of Collaboration	Violations of Individualized Programming
-Practices Discouraging Parental Involvement: (Family 1, 2, 3, 4, & 5) *Feelings of Intimidation *Feelings of Discomfort/Embarrassment *Not Feeling Like Equal Members *Not Feeling Respected *Negative/Incontinent IEP Meetings *Teacher Turnover -Practices Encouraging Parental Involvement: (Family 1, 2, 3, 4, & 5) *Staff wanting to Work with My Child *Child Attending the IEP Meeting *Having a Shared Vision *Feeling Included in the Process *IEP Meetings Focusing on the Positive *On-going Training for Parents -School Personnel Attitudes (Family 1, 2, 3, & 4)	-Similar Goals for All Students (Family 1, 2, 3, 4, & 5) -Narrowly Focused Transition Services & Post-School Outcomes (Family 1, 2, 3, 4, & 5) -Centered-Based School Programs (Family 1, 3, 4, & 5) -Assignments of Paraprofessionals to All Students with Similar Labels (Family 1, 2, 3, & 4)
Failure to Acknowledge Wishes of Family Members	On-Going Family Issues
-Discrepancies Between Parental Expectations of Services & Actual Services Provided (Family 1, 2, 3, 4, & 5) -IEP Goals & Services Based on School Expectations (Family 1, 2, 3, 4, & 5) -Post-School Plans for Child's Future Life Based on Traditional Options (Family 1, 2, 3, 4, & 5)	-Other Children in the Family (Family 1, 2, 3, 4, & 5) -Adopted Children (Family 4) -Unexpected Death of Family Member (Family 1) -Parents Both Working Full-Time (Family 2) -Lack of Support from Family & Friends (Family 3) -Coordinating Between Divorced Parents (Family 1) -Health Concerns of Parent (Family 4) -Marital Problems (Family 5) -Substance Abuse in Family (Family 5)

Actions/Interactions

The next component of the paradigm model shown in Figure 1 of the grounded theory process is action/interaction. Actions and/or interactions have been described as the specific “strategies devised to manage, handle, carry out, [and/or] respond to a phenomenon under a specific set of perceived conditions” (Strauss & Corbin, 1990, p. 97). Actions and interactions are always evolving and changing. They are typically performed with a specific purpose or goal in mind, and they take place through the development of strategies. In the model proposed here, actions and interactions are invariably driven by the phenomenon (i.e., the parents’ wish for children to be reflections of themselves). Yet, they are also guided by, and are in response to, the intervening conditions.

Additionally, *not* acting or interacting in a specific way can be important. “In other words, if someone should, or ordinarily would do something in a situation and he or she doesn’t, then we must ask why?” (Strauss & Corbin, 1990, p. 104). And, as mentioned previously, there are intervening conditions that either facilitate or constrain a participant’s actions and/or interactions.

The following actions and/or interactions were taken by participants in this study while planning for the future lives of their sons or daughters: pushing for better educational experiences, accepting less than desirable services, searching for post-secondary resources on their own, starting a family business, going through the motions to get through meaningless legal requirements, and accepting their child’s disability.

Pushing for Better Educational Experiences

The first action and/or interaction taken by these participants was pushing for better educational experiences for their children. This action/interaction was something that happened throughout their children's educational experience but was something that parents did at this particular period of time in order to help their children reach the goals or expectations that they had for their future lives. All of the families showed strong evidence of this action/interaction. Parents went about pushing for better educational experiences in different ways. For example, Latoya said when she wanted the school to try something new with her son or provide a specific service to her son, she would passively make suggestions of things she felt would make things better for him or easier on the school. She felt like this approach was more successful in getting the school to implement what she was asking for than telling them what to do. She explained:

I try to very tactfully relate my wishes to them. You know, "I think [Jamar] could . . ." I try not to approach it as telling them what to do. But I always approach it from, "[Jamar] needs . . ." or "[Jamar] might be really good at this." It's hard to be really firm. I'm kind of wishy-washy that way. I'm sorry but I am always very cautious about the way I put it because if you say it the wrong way, then for sure that's going to be cut down. If they think you are telling them what to do, nobody's going to listen.

Another way that she went about pushing for better educational experiences for her son was by trying to educate school personnel about different resources or options that were available to all of the children being providing services in the life skills program, not only her son. For example, because she had an expectation for Jamar to participate in some type of post-secondary education experience she planned to give her son's special education teacher information on the different post-secondary education

programs available to students with significant disabilities in hopes that the teacher would also consider this option for other students in the program.

The next way that parents went about pushing for better educational experiences was by having their children attend and be involved in their own IEP meetings. Although this is something mandated by law, many times students who have significant disabilities, in particular those with limited expressive language skills, are not adequately included in this planning process. Parents reported feeling like this was something that not only helped the tone of the IEP meetings to be more collaborative, but was also something that benefited their children. For example, Latoya described:

Involving him in the transition process is probably the most important part. In the past, he has not been included in IEP process. I mean, all through elementary school and really a lot through middle school, too. He was there for five minutes and nobody talked to him. He was talked about and so then he'd get up and leave the room because we were all sitting around the table talking about him and he wasn't involved. So, I want some meaningful involvement for him because he's going to have to make his own decisions. I always say that IEPs are not something that you should be doing to the child. It's something for the child and they have to buy into it. So here we are making all these goals for him and he's not involved. How's he going to buy in?

Another way that parents tried to push for better educational experiences was by bringing food to the IEP meetings. Rosa, Celina's mom, felt like bringing food to the IEP meeting was something that helped to set a more positive tone. She shared:

I usually try to take something to my IEP meetings whether it's a little dish of candy or some cookies or rolls. I just always believed in food as a hospitality support. I've also always, especially when I knew things weren't going to be good. These were in the early days of [Celina] being in the regular classroom when I especially took food because I knew we were going to have to melt the ice a little bit.

Asking the special education teacher to provide homework for her son was another way that Nina, Koda's mom, tried to push for better educational experiences. She

felt like if she could help her son practice some of the skills he was working on at school then he might be able to make more progress. She explained:

We go in and they tell us that he works on telling time and counting money and things like that but when I sit him down and try to ask him things like that it's not there. So I asked his teacher to start sending home homework papers that he would normally do at school, to send them home as homework. He did that for about two or three months and then it just stopped because it was an extra responsibility. So when we go in there to visit [Koda] at school, he's just sitting or he's playing on the internet or looking at a magazine or something like that. He's not doing anything educational. That's why I get so upset with the school.

The next action/interaction strategy used by parents in this study to push for better educational experiences for their children was pushing for their children to have more typical peer interactions or to be included in general education environments more often. For example, Rosa said that she wanted her daughter included in general education environments because it would be better for them once they exited the school system. She stated, *"Inclusion is the way we want to go. A lot of families don't choose inclusion. We have chosen inclusion for our girls because we feel it will prepare them better for the real world."* Latoya, Jamar's mom, also fought for her son to be included as much as possible with his typical peers. She explained:

I did a lot of fighting for inclusion and so throughout his elementary school years I had him at his neighborhood school not in a specialized program. Middle school I had him in his neighborhood school and he was the child with the most significant needs in the school and so when it came to high school every high school has a life skills program and so that's where he is and I'm trying to think of ways right now of how I might get him integrated more into the school community because the life skills program is down in the corner and it has two rooms and they barely go out and everybody else is around the building. We have got to let him have more time with peers and I suggest things like, "Can a peer meet him or work with him on this?" "Nope he can't do that. Nope he can't do that." I'm thinking we want an opportunity for having some more peer interaction. Not just peers with disabilities but all kinds of peers.

Accepting Less Than Desirable Services

The second action and/or interaction taken by participants was accepting less than desirable services. This acceptance generally took place after participants experienced some kind of negative interaction with school personnel or after fighting for something they wanted for their children without successfully receiving it, such as being included in general education environments. All of the participants in this study admitted to accepting less than desirable services for their children at some point in their educational experience. One example of this was Karina, César's mom, who admitted to accepting less than desirable services for her son after having to fight for her son to be provided school based services after moving to a new school district. As previously mentioned, after moving back to their old school district, they agreed to have their son moved into the transition program early. Karina discussed how she accepted the services the school proposed because she was happy that they wanted to work with him. She explained:

Because I have so many problems with the other district, I think okay one day I am going to go in and they are going to tell me you know, your son did change. We can't bring him back. So that was my fear. Transition, probably since we didn't have nothing before, was the best thing that we got. Of course it is always something that I would want to have more. It was nice to see how every single person was willing to work with me and you could tell they were proud of themselves on what they accomplish and those little things were enough for me. Maybe you say oh you were not expecting too much from the school but from the things I went through, having people that are happy to be working with him, that was enough. Even if they are not accomplishing anything, even if they are not working on anything, you know, seeing that they are happy with him it was just enough for us. We are happy with what we get from the transition program.

Searching for Post-School Resources On Own

The next action and/or interaction taken by participants was searching for post-school resources on their own. Participants reported taking this action because they felt

the school did not provide them with post-school resources and/or the post-school resources that were provided did not sufficiently meet the expectations for their children's future lives. All participants reported taking this action/interaction when preparing for the transition of their children out of the school system.

Nina, Koda's mom, felt like the school district did not try to provide them with post-school resources that might be helpful for their son. She felt like she has had to look for resources for his future life on her own. She stated:

Right now, the school, all they have really done is get us in touch with voc rehab and that's basically it. Everything else that [Koda] has, I've done. The school didn't even bother to help us in getting him enrolled in day services. I did that all on my own. I knew that there was a waiting list for the group home and I knew that he should have been on the waiting list from like age eleven. So I mean nobody really gave me the information that I have. I had to investigate myself and everything that I know and that I have done for him is because I dig and I know there are things out there.

Maria, Esperanza's mom, also felt like she has had to search for post-school resources on her own. She admitted that the school has given her some information on post-school resources but what they have given her has not been current. She explained:

I have been doing a lot of research. I have done a lot to educate myself with this system. I would just like to have resources that are actually out there. I have a sheet of resources that the school gave me and some of them aren't even in business anymore. They don't even know this system.

Other participants felt like they could not just wait around for the school to provide them with resources and supports for their children's future lives. Instead, they took it upon themselves to search out resources that they felt would best support their children in reaching their expectations and goals and ensured that these sources of support were in place. Rosa, Celina's mom, described the resources she has put into place for her children since she found out that she was dying of cancer. She shared:

We started a special needs trust for the girls. So we have that in place. It will be funded on a life insurance policy on me. So when I go there will be some money there for them to be able to use to hire people, buy a new bed if they need a new bed, maybe send them on a weekend trip, or something like that, you know, take care of their non-basic needs. So we've done that.

As mentioned previously, Latoya, Jamar's mom, also researched different programs that provide the college experience to students with significant disabilities because this was one of the expectations that she had for her son. She also admitted that she was not expecting the school to tell her about these resources since she felt like this expectation was not an expectation that school staff shared with her.

Starting a Family Business

Another action and/or interaction taken by one particular family was starting a family owned business. One family reported taking this action/interaction when preparing for their children to transition out of the school system. Rosa, Celina's mom, explained that one of their main expectations for all of their children was that they become productive members of society through employment. Because of this expectation they decided to start their own family business. This was due in part to the limited options for employment available to individuals with significant disabilities. She explained:

We built that business so that they have a place to be productive because I don't see a whole lot of the world helping them be productive yet. I mean you have Wal-Mart greeters and you have McDonald's workers and all the typical stuff but I think we've got a niche in the printing industry that is good for them.

Getting through Meaningless Legal Requirements

The next action and/or interaction was going through the motions to get through meaningless legal requirements. Again, most participants in this study admitted to having this reaction to negative experiences they had within the educational system at different

points along their children's school journey. For example, Latoya discussed her feelings of the meaningless legal requirements of the IEP process for her son, Jamar. She stated:

The IEP is meaningless to me. They are not useful for me, as a parent, much less a classroom teacher, you know, that might have him in their class. So there's got to be a better way. They've got to be more functional. I don't know if the IEP meeting is the most conducive place to start discussing something like post-school outcomes and transition goals. You know, they say, "sure, we'll put that in the IEP. That's a goal." And then there is every reason in the world that we couldn't meet that goal. So IEPs have not been good to me.

Along with the negative experiences parents had within the school system, sometimes the reaction of going through the motions to get through meaningless legal requirements was influenced by events taking place in their own lives. As previously mentioned, this was especially true for Rosa, Celina's mom, who had been recently diagnosed with cancer. She shared:

It's like me now, you know. Like in the scope of what's important in my life today. How important are those IEPs? Not very important. Not very important. I mean, I'm making sure that they're done. I'm making sure that they are okay. But there's no way that I'm going to be out there monitoring that it gets done. We'll just go to the next meeting and I'll have my feel about whether it gets followed or not. You know, it's a formality that we have to go through to get what support we get for the kids to be in a regular public school. Not ever a regular classroom like the law says they're supposed to be. Just to be in a regular school you gotta go do this.

Another reason why participants reacted by going through the motions to get through meaningless legal requirements was because they felt like it was too late to do anything to improve their current situation with the school or their child's services. Nina, Koda's mom, explained:

You know at this point it is kind of too late because I stepped in kind of late in his life and by then the damage had already been done so basically right now I am just letting him go through the motions. I let him go through the motions this year so that we could graduate him and I will do what I feel needs to be done after that point because the school has slacked so long with him that I mean it is pointless.

Accepting their Child's Disability

The final action and/or interaction was acceptance of their child's disability. Two of the families reported taking this action/interaction when it came to planning for the future life of their children with significant disabilities. Latoya, Jamar's mom, felt that one of the biggest barriers to her son reaching the expectations and goals for his future life was the idea that there was something about him that needed to be fixed in order for him to be a successful member of society. She shared:

You know lot of people look at him and they say if we fix these things about him it will be okay and I keep thinking I don't want it to be fixed. So there are some things that we will have to accept about him and it's not a problem for society for him to be doing flipping every now and then or jump up and down because he needs to get some kind of activity but trying to squelch that in him and then say, "now you can go out to the community and it is okay." It makes me kind of concerned. It is like telling people, "I want you to stop breathing and then you can go out to the community." So I see that as an issue but he's capable of going out into the community and I think he's going to surprise everybody given the opportunity.

Maria, Esperanza's mom, said that she felt this same way about her daughter. She explained:

In the beginning, I wanted them to fix her that was their job. I kept telling them, "You need to fix her. You need to fix her." And I came to the realization that she never needed to be fixed. She needed to be supported because this is who she is and I finally got that.

Summary of Action/Interaction

In summary, the actions and/or interactions, which are reviewed in Table 6, were specific strategies participants used to try and realize their expectations and goals for their children's future lives. These actions and/or interactions, driven by the desire to have their children's lives mirror their own, were ever changing. These changes were dependent on the context in which they occurred and the presence of intervening

conditions such as negative experiences they had within the school system, on-going family issues, and limited opportunities and resources. Actions and/or interactions led to specific outcomes, intended or otherwise, which are discussed in the next section.

Table 6

Actions/Interactions Taken in Response to Phenomenon

Actions/Interactions	Families
-Pushing for Better Educational Experiences	-Family 1, 2, 3, 4, & 5
-Accepting Less Than Desirable Services	-Family 1, 2, 3, 4, & 5
-Searching for Post-School Resources On Own	-Family 1, 2, 3, 4, & 5
-Starting a Family Business	-Family 4
-Going Through the Motions to Get Through Meaningless Legal Requirements	-Family 3, 4, & 5
-Accepting Their Child's Disability	-Family 1 & 3

Consequences

Strauss and Corbin (1990) defined consequences as, “action and interaction taken in response to, or to manage, a phenomenon have certain outcomes” (p. 106). The final component of the paradigm model is consequences, which are the outcomes of action/interaction strategies taken by participants in the study. Such outcomes might be positive, negative, or neutral (Creswell, 1998) and might not always be predictable or reflect what was intended (Strauss & Corbin, 1990).

The failure to take action/interaction also had outcomes or consequences for these participants. These consequences of inaction could then become part of the contextual or intervening conditions affecting the next set of action/interaction occurring in a sequence. Therefore, what are consequences of action/interaction at one point in time may become part of the conditions in another. There were two specific consequences to the actions/interactions taken by participants in this study: feelings of empowerment and feelings of defeat.

Feelings of Empowerment

Feelings of empowerment were those specific outcomes or consequences that existed because of specific actions and/or interactions taken by the participants. Feeling of empowerment can be defined as gaining the skills or knowledge to overcome obstacles in life (Blanchard, Carlos, & Randolph, 1996). Someone who is empowered has the capability to make decisions about their circumstances, can access information and resources, has the ability to be assertive during decision making, and believes in his/her ability to make change. Often empowerment focuses on eliminating the need to rely on others for help. The participants in this study experienced feelings of empowerment when they pushed for better educational experiences, searched for post-school resources on their own, started a family business, and accepted their children's disabilities as characteristics that did not need to be fixed. These actions and/or interactions led to two specific feelings of empowerment: feelings of being in control of the situation and feelings of security for the future.

Feelings of Control. Participants had feelings of being in control of the situation when they used certain strategies. These actions and/or interactions strategies included

pushing for better educational experiences, searching for post-school resources on their own, and accepting their child's disability as a characteristic that does not need to be fixed. When pushing for better educational experiences, Maria, Esperanza's mom, discussed actions and/or interactions that she took that allowed her to feel like she was in control of the situation. She explained, *"I do let them know how I feel and I do let them know that [Esperanza] is entitled to certain things."* She also stated, *"Those meetings can get really frustrating but I stand my ground in a positive way. I am not a difficult mom. I would just say, 'No.' or 'I'm not signing that.' Or I would bring someone to help me."* Karina, César's mom, also described actions and/or interactions strategies that she took that allowed her to feel more in control of the situation. She explained:

I was the person that was more involved, especially with [César]. I was the one who was fighting for his rights and, you know, what he deserves all these years. It was what he deserved and it has to be served right away. But at least I able to work and you know push them to do something and get my point across.

One thing she did was to request her son's IEP meetings be held at their home. She shares, *"Mostly the IEP meetings were here at home. I say I want them here at home since I have more kids and my hours are very tight, you know, running all day. So they always came over here."* Latoya, Jamar's mom, also discussed actions and/or interactions that she took that helped her to feel more in control of her son's educational experiences. As mentioned earlier she tried to approach school staff with suggestions or ideas that might be helpful for them to use with her son. She felt like if she told them what she would like them to do, they would not do it. She stated:

I sometimes find that the IEP is not what drives a lot of the instruction. It's the constant communication outside of the IEP meeting that helps. Like, "wow, that's a really cool activity. I thought [Jamar] could do blah, blah, blah," and so they do it and it's like, "he did it. Look at this. Look what he did." So sometimes it's

not the IEP that's the driving force. Sometimes it's you know, put it on the back burner. I'll talk to you directly and I'll say, "You know, why don't you try this?"

When searching for post-school resources on their own, several participants discussed actions and/or interactions that they took that allowed them to feel like they were in control of the situation. For example, Rosa, Celina's mom, described how she has tried to make sure that her girls have the necessary supports and services in place for their future lives. She explained:

I'm a control freak. I'm a mom. I'm trying to, as much as I can, put everything into place so that when I leave they don't have to worry about it. But there is going to be plenty for them to worry about. It is just that those really important pieces I want to have a say in them and I want to be able to put the processes in place so that all they have to do is pick up where I left off.

Nina, Koda's mom, also discussed the actions and/or interactions that she took to feel in control of her son's transition out of high school. As previously discussed, she did not feel like the school was doing anything academic for her son and she also felt like they were not doing anything that would help him to be successful after he left the school system. So she took it upon her self to find and put into place post-school services for Koda. She stated:

Nobody told me about any of the services. I just found all this information out on my own. Like I said I have kind of given up on them. I have done everything for my son on my own. I don't rely on the school at all because I don't feel like they were meeting my expectations like I think they should. I will pick up the slack because I care about my son and if they can't step up and do it, then don't. That is just the way I feel about it.

Finally, several participants discussed their actions and/or interactions of accepting their children's disabilities as something that did not need to be changed or fixed. These actions and/or interactions led them to feel like they were more in control of the situation. This acceptance allowed participants to be open to developing new or

different expectations and goals for their children with significant disabilities or to explore ways that their children could still meet their original expectations and goals in a different way.

Feelings of Security. Along with feeling like they had more control of the situation, participants also had feelings of security for the future when they used specific action/interaction strategies. These strategies included starting a family business and searching for post-school resources on their own. As previously discussed Celina's parents, Rosa and her husband, started a family business. One reason they started this business was their disappointment in the employment options available to individuals with severe disabilities, and they felt like their business would be a good employment option for their children with disabilities. It has become a great sense of security for Rosa and her family. She explained:

The school knows we have the business. We've made that very upfront. Hey eventually they've got that. Not that we are going to impose that on them if it doesn't work out. I mean I'm not hell bent on they must work at the shop but we built that business so that they have a place to be productive. Because we have our own business, we are not dealing with them sitting at home watching TV all day long. They have a place to go during the day and it's going to be a place that is supported by people who care about them, not by strangers or, you know, people who come and go, or be there for six months and then leave and then come back and then leave and hire somebody else. That's really what's going to make it different for us so far has been that we have a family business and the other kids have been able to just, you know, transition right into it and we expect that the girls should be able to do that as well.

Participants also discussed actions and/or interactions they took to find post-school resources for their children with significant disabilities. These actions and/or interaction strategies not only helped participants feel more in control of the situation but it also helped them to have feelings of security for the future. As previously mentioned,

Nina, Koda's mom, has searched for post-school resources for her son. Finding these resources helped her to feel more secure about her son's future life. She explained:

I knew that there was a waiting list and I knew that he should have been on the waiting list from like age eleven. I mean nobody really gave me that information. So he's on the waiting list for the group home, now. But when a child is diagnosed you need to start pulling resources because it's never too early but it can be too late.

Rosa, Celina's mom, also discussed resources that she has put into place so that she can feel secure about her daughter's future life. She shared:

[Celina's] on the waiting list for adult services and we have pretty much left the house as kind of their safety net so that when we are gone they have a place that they don't have to move out of. My expectations are that my children without disabilities will be damn good advocates and that they will be there to be sure that they're well cared for and that the people who come into their life are good people and care about them. You know, I think again we've got family on both sides so there's going to be a lot of family involvement but at some point I feel the need to put into place some structure, paid people who aren't family because I don't want my family to feel like they have to do it. I want them to know that if they can't, we got this person over here that we can pay to do it.

Feelings of Defeat

Feelings of defeat were those specific outcomes or consequences that existed because of certain actions and/or interactions strategies taken by participants. Feelings of defeat can be defined as unsuccessful endings to challenges and struggles or the feelings that accompany an experience of being thwarted in obtain your goals or eliminating something that is expected. Thus, feelings of defeat are essentially the opposite of feelings of empowerment. The participants in this study experienced feelings of defeat when they pushed for better educational experiences, searched for post-school resources on their own, accepted less than desirable services, and went through the motions to get through meaningless legal requirements. These actions and/or interactions led to specific

feelings of defeat including feelings of mistrust, fear, and anxiety, feelings of dissatisfaction and resignation, and feelings of isolation.

Feelings of Mistrust, Fear, and Anxiety. Participants expressed feelings of mistrust, fear, and anxiety when they took certain action and/or interaction strategies. These strategies included pushing for better educational experiences and searching for post-school resources on their own. Because of the educational experiences that Esperanza has gone through, when it comes to pushing for better educational experiences, Maria admitted to not being able to trust anyone. She stated:

My kids are my life. I mean any parent can say that but with [Esperanza] there is just no way that someone is going to meet her. I don't let just anyone meet her. I've got to know that this person is sincere. I can't trust anyone. As long as I know my daughter is safe I'm fine but I can't change the world.

Likewise, when searching for post-school resources, participants also admitted to having feelings of mistrust. Latoya, Jamar's mom, described her feelings of mistrust and fear when it came to her son being able to live independently when he gets out of school. She explained:

I guess my other concern is somebody needs to check to make sure that nobody is taking advantage of him. I guess that's kind of my greatest fear is that somebody will take advantage and he won't be able to communicate. You know, "what happened to all my money" or "who are these people living in my house" and there are so many potential problems there. I want him to be safe. I don't want people taking advantage of him.

When searching for post-school resources, Nina, Koda's mom, also admitted to having feelings of mistrust when it came to her son being out in the community and her concerns about how he will be treated. She shared:

It's a trust thing. I think when you are dealing with children that have developmental delays it's like we want to keep it in the home. We don't want anybody to know. We don't want anybody involved. We want to do it on our own. Because of the way we were raised. You know, it's totally different now but

because of the way we were raised, we just feel differently about it. We don't want him to be labeled retarded. We don't want him made fun of and having a hard life and in a way I shelter him and don't want that for him. It's hard.

Maria, Esperanza's mom, also admitted to having feelings of fear and anxiety for her daughter's transition into the adult world. She explained:

It's like, life is getting harder now and now that the huge transition is coming up it is kind of freaking me out. I'm starting to get into the adult arena but it scares me because I feel like they get dumped and that is what scares me is that now we are really going to be on our own. We are really not going to have the support that we did. I worry because she is older and do they want to take advantage of her? I worry about someone not understanding her when she is trying to communicate something. I worry about someone hurting her. Like if she was to go out and someone actually hurt her because they didn't understand. I hear all the time that cops shot someone, you know, that guy that was deaf and killed him because he couldn't hear and the one at that residential treatment facility who didn't want to eat and they took him down and he died of asphyxiation because he didn't want to eat. You know, I worry about it. Look at [Esperanza], it happened to her. It happened to her at school. She didn't want to eat now she has a fractured skull and they don't even care. So we have already been there. It is like I worry about that. I worry about that all the time.

Feelings of Dissatisfaction and Resignation. Participants also discussed feelings of dissatisfaction and resignation when they took certain actions and/or interactions. These actions and/or interactions included pushing for better educational experiences, accepting less than desirable services, and going through the motions to get through meaningless legal requirements. When participants took actions to push for better educational experiences for their children, as mentioned above, sometime this led them to feel like they were in control of the situation. However, sometimes pushing for better educational experiences resulted in no change in services which left these parents feeling dissatisfied and ready to give up. After years of fighting with the school system to provide her daughter with appropriate educational services, Maria, Esperanza's mom, admitted to not feeling satisfied. She stated:

I promised myself I wasn't going to cry another time, not because of [Esperanza]. I'm going to be happy now and that's behind us but the pain is still there. The hurt is still there. I've been through a lot. We've been through so much and nothing has changed.

Latoya, Jamar's mom, also described her feelings of dissatisfaction and resignation after going through the legal requirements of the IEP process. She shared:

I feel like I've gotten worn down. It's like for Pete's sake I can tell you this until I'm blue in the face and no one is going to listen. But most of the time it's like, you know, at this point, I'm so worn down by this process. Rather than being the positive process that everybody I know, that works at the administrative state level, they say, "You know, it should be a really constructive process." Um, in practice, it's not.

After years of fighting the school district to keep her daughters out of the Challenge Program, Rosa, Celina's mom, admitted to having feelings of resignation when the school would not back her up against a teacher who refused to have her daughter in her class and she accepted less than desirable services for her daughters. She tearfully explained:

That was a huge defeat for me. [crying] I really believe that my kids should have graduated from that school. She had three good years of being included. I had people, teachers, stopping me and saying, "Thanks to you, I learned how to do better for my whole class." I was like, "Yes. I'm right. This is the right thing to do." Then when they wouldn't back me up, towards this teacher, I was devastated. I was really, literally at that point is where my husband and I just threw our hands up and said, "I guess the challenge program is for us." And we went over there and we dealt with the challenge program. Not what we wanted. We settled for it. We settled for it because, even then before I even got sick, we were under as much stress as everybody else, two working parents. You know, by then it wasn't like I could just quit my job and be a helicopter parent, although, I spent a lot of time over there. I took a lot of time out of my work. There was a period of time when I came every single morning and I supported her through the entry, the hello, the whole bit just so that teacher wouldn't have the burden. I did a lot to try to make that happen and then when it didn't happen, we settled for what we got. We could have probably fought more. I imagine we could have gone to due process. But, you know, I see due process as not what it's all chalked up to be and you take a school to due process and you say, "We won. Here's my kid." I didn't want that either. I'd just as soon have them someplace where at least they accept them. And, you know, again in retrospect of where I am today,

looking back, I think to myself, "In the scheme of things, how much of any of what I have done really matter to [Celina] and [Marcella]?" Because they would be happy with whatever. You know, I don't think that that alters how any of us should go about fighting for what we believe is right. But in the grander scheme of things, [Celina] will come home and she is just as happy as a clam being in the challenge program and she would be if I had her in the regular program. One hundred percent of the time [Marcella] comes home just exuberant about everything. Challenge including regular. So in the scheme of things you know, you just finally kinda say, "Hey. It's not about me. It's about them." So I think, in some respects, [My husband] and I have probably chosen to take the easier way out. Just because I don't think I could have dealt with it. I know parents that have fought it to the very end to have their kids included. I mean I can name some other people that have fought to have their kids included in the regular classroom and I admire them. And you know, I still believe, I still believe that the regular classroom can benefit, a lot from these kids. [crying] So, I hate to say that in some ways I preach one thing and I do another. Um it's been very hard to keep them out of that place and believe me today they're at special Olympics, both of them, but I'm at a point in my life too where I just can't fight everything. I can't turn everything I want into a battle. We really have tried our best to get as quality as we can. But they are still products of the challenge program and I think as long as there are going to be challenge programs, you are going to have this situation exist. Until the day that they do away with the programs and truly make all of that look like it doesn't exist, I don't think we are going to get what it is that I hoped for. I really don't.

Nina, Koda's mom, also admits to giving up on the school ever helping her son to become successful or getting the necessary supports in place for him to be successful when he leaves the school system. She stated:

You know at this point it is kind of too late because I stepped in kind of late in his life and by then the damage had already been done so basically right now I am just letting him go through the motions. I let him go through the motions this year so that we could graduate him and I will do what I feel needs to be done after that point because the school has slacked so long with him that I mean it is pointless. I can make the decisions for my son. I feel that I know what is best for him and I know what he needs. So I will just do it for him. Like I said I just kind of gave up on the school because I had gone to all those IEP meetings and never got anywhere. So I just let him go to school just so that he could get the days in and I teach him at home. The school gave up on my son so I gave up on the school. The damage is already done. You know, I put ten years of work into the last two years because he didn't have SSI, so he wouldn't have had any income when he turned eighteen. He wouldn't have had any job training. He wouldn't have had anything.

Feelings of Isolation. Finally, participants discussed their feelings of isolation when they took certain actions and/or interactions in response to their expectations and goals for the future lives of their children with significant disabilities. These actions and/or interactions included searching for post-school resources on their own and pushing for better educational experiences. All of these actions and/or interactions led to the same feelings of isolation for the future. After searching for post-school resources, Maria, Esperanza's mom, describes her feelings of isolation for her daughter's future life based on the limited options that existed. She explained:

Sometimes I see her and how she's great and an awesome kid and I thank God that he didn't take her and then there's those days where she doesn't have friends and her behavior has gotten worse so people don't like being around her. She doesn't really do a lot. She doesn't get invited anywhere, except for her stepdad, me, her brother, her dad, and my mom, that's all she has in her life and it's like I feel bad because that is not how life is supposed to be and I try to get her out and I try to do stuff and we do, do stuff but we do it separate. I mean people with disabilities go out, get a job. Some of them go to college. I mean they are verbal, they are mobile, they understand, they comprehend, [Esperanza] is different. I don't want to say she will have no life because she will have a life but I feel bad for her because she has no place to go. I mean she is stuck with just the three or four of us or whoever comes in contact with us. I feel like we are going to be really isolated. That is my fear the isolation.

After visiting some adult day programs designed to provide services to individuals with significant disabilities, Karina, César's mom, also admitted to feeling like the options available were not what she wanted and that they were very isolating. She stated:

Sometimes people think that because he is not going to have a real life they don't realize where they are. It's hard, you know. Even the way I dress him, you know, he is always clean and everything. Because I don't know if he realizes it but I realize and I don't want him to be alone, you know, like the abandoned kids.

Despite pushing for her daughter to be included in general education environments throughout her school years, Rosa, Celina's mom, expressed her concern about the isolation that she foresees in her daughter's future life. She explained:

No one takes an interest in these kids. So often we parents suffer more than they do because we want so much for them and it doesn't happen and yet, they're happy with whatever. She seems to be very happy at school but she doesn't have friends coming over. You know, she's not invited anywhere. So [Celina's] social life, pretty much, is her family.

Summary of Consequences

In summary, consequences were the outcomes of the actions and/or the interactions participants performed in relation to their expectations and goals for their children and in response to the intervening conditions. Two categories of consequences were identified in this theoretical model: feelings of empowerment and feelings of defeat. These outcomes were not always predictable and they may or may not have been what the participants intended. Nevertheless they were what happened when participants acted or interacted in particular ways.

In this section a variety of different feelings related to empowerment and defeat were described. These specific feelings are reiterated in direct relation to specific actions and/or interactions of the participants. As Table 7 suggests, feelings of defeat seemed somewhat more frequently than feelings of empowerment for this group of participants.

Summary

This study was designed to explore culturally and linguistically diverse parental perspectives of transition services being provided to their children with significant disabilities. The primary question being addressed in this research is:

What are the experiences and perspectives of parents who are culturally and linguistically diverse on the transition services being provided to their children with significant disabilities?

Table 7

Consequences Produced By Actions/Interactions

Feelings of Empowerment	Actions/Interactions	Feelings of Defeat
-Feelings of Control (Family 1, 2, 3, 4, & 5)	*Pushing for Better Educational Experiences (Family 1, 2, 3, 4, & 5)	-Feelings of Mistrust, Fear, & Anxiety (Family 1, 3, & 5)
		-Feelings of Dissatisfaction & Resignation (Family 1, 3, 4, & 5)
		-Feelings of Isolation (Family 1, 2, 3, & 4)
	*Accepting Less Than Desirable Services (Family 1, 2, 3, 4, & 5)	-Feelings of Dissatisfaction & Resignation (Family 1, 2, 3, 4, & 5)
-Feelings of Control (Family 1, 2, 3, 4, & 5)	*Searching for Post-School Resources On Own (Family 1, 2, 3, 4, & 5)	-Feelings of Mistrust, Fear, & Anxiety (Family 1, 2, & 3)
-Feelings of Security (Family 4, & 5)		-Feelings of Isolation (Family 1, 2, 3, & 5)
-Feelings of Security (Family 4)	*Starting a Family Business (Family 4)	
	*Going Through the Motions to Get Through Meaningless Requirements (Family 3, 4, & 5)	-Feelings of Mistrust, Fear, & Anxiety (Family 3, 4, & 5)
-Feelings of Control (Family 1 & 3)	*Accepting Their Child's Disability (Family 1 & 3)	

To answer this question a logic model was developed to organize participants' experiences and perspectives of the transition services being provided to their children. This model was designed to be consistent with the six components of the grounded theory process (Strauss & Corbin, 1990). These components are: (a) causal conditions; (b) phenomenon; (c) intervening conditions; (d) context; (e) action/interaction; and (f) consequences resulting from the action/interaction. This visual representation of the experiences of these families offers a deeper understanding of the challenges, actions, and consequences they faced during the transition period.

The centerpiece of this model, the phenomenon, was that parents perceived their children as extensions of themselves, and they attempted to *act* accordingly. Their perceptions were controlled by particular causal conditions; mainly values based on past experiences and their views of disability. When parents attempted to act and interact on behalf of their children, they must do so in relation to certain intervening conditions, which included their ongoing experiences with systems and the availability of resources and opportunities. They must also conduct their actions and interactions within a context that included variables related to school programs and ongoing family issues. Their resulting actions and/or interactions, attenuated by intervening conditions and by contextual factors, can result in feelings of empowerment, but more frequently for this sample of parents, in feelings of defeat. These represent the consequences of the actions that they have taken on behalf of their children.

The next chapter will summarize and provide selected elaborations of the model that has been developed here, with implications for current educational practices and

teacher preparation. Limitations and recommendations for future research in this area will also be discussed.

CHAPTER VI

DISCUSSION

Introduction

The purpose of this study was to investigate culturally diverse parental perspectives and experiences with the transition services provided to their children with significant disabilities. Parents' expectations can be a powerful predictor of positive outcomes; however, recent research continues to report negative post-school outcomes for these students (Blackorby et al., 2007; Wagner et al., 2005; 2006). Studies have also reported comparatively less involvement from parents from ethnically and culturally diverse backgrounds (Garriott et al., 2000; Geenen et al., 2001; Salembier & Furney, 1997) and these studies have not adequately addressed the experiences and perceptions of parents that represent both minority cultures and significant disabilities in the transition processes.

Grounded theory methodology was employed to investigate parental perspectives. The use of multiple in-depth interviews was the primary data collection tool and a total of 327 pages of transcribed data were yielded from the interviews. The data were coded using open, axial, and selective coding procedures. It was then reconstructed using the constant comparative method and organized into the six components of the paradigm model of the grounded theory process (Creswell, 1998; Strauss & Corbin, 1990). These components include: (a) causal conditions; (b) phenomenon; (c) intervening conditions;

(d) context; (e) action/interaction; and (f) consequences resulting from the action/interaction. These components were then organized using a visual model that provided a framework for understanding and explaining the perspectives and experiences of participants.

The remainder of this chapter summarizes and further elaborates on the components of the paradigm model of the grounded theory process. This involves connecting the present theory produced from these data to implications for current educational and personnel preparation programs, as well as reform of adult agency services. Recommendations for future research in the area of transition services for students with significant disabilities who are culturally diverse are presented. Possible limitations of this research are discussed and finally, conclusions drawn from these data are shared.

Connecting Theory to Practice: A Review of the Grounded Theory Model

The theoretical model developed from this work (see Figure 1 in Chapter V), consisting of the six components of the paradigm model of the grounded theory process, painted a picture of parents' progression from their own childhood, upbringing, and cultural backgrounds through the moments of realization of their children's disabilities, and through the development of strategies to manage, deal, and survive transition planning for the post-school lives of their children with significant disabilities. In the end, these strategies helped participants move through the often disappointing effects associated with the phenomenon of envisioning their children as reflections and/or extensions of themselves and then not having their expectations realized.

The theoretical reconstruction of these data provided a groundwork for a broader understanding of the transition process as it was experienced by parents and provided a deeper understanding of the transition process that many families must go through during this critical time in their children's lives. Hence, a deeper examination of the six components of this model can provide the field with principles, strategies, and guidelines for enhancing its services. This task is what is accomplished over the next six sub-sections.

Effects of the Causal Conditions

The participants' values and beliefs based on their past experiences and their views of disability in general served as the causal conditions in this theoretical model. Essentially, these causal conditions were contributing factors associated with their cultural backgrounds. Culture has been defined as the "ideals, values, and assumptions about life that are widely shared among people and that guide specific behaviors" (Brislin, 1993, p. 4). These cultural values and beliefs influenced the way each participant defined a successful adult life for their children, thus influencing the expectations and goals they had for them. Therefore, their past experiences, expectations, and views placed on them during their upbringing led to the development of what they currently value or believe to be important in helping their children with significant disabilities become successful adults.

Ultimately, parents' cultural backgrounds, their cultural values and beliefs, lead to post-school expectations and goals they held for their children, including their child with a significant disability. This is true for parents who come from a minority cultural background as well as for parents who come from majority cultures. "Culture is not just

something that someone else has. All of us have a culture, ethnic, racial, linguistic, and religious (or nonreligious) heritage that influences our current beliefs, values, and behaviors” (Lynch & Hanson, 2004, p. 76).

In fact, Hidalgo (1993) has suggested that there are multiple levels that need to be considered when defining culture. First is the *Concrete* level, which includes things that can be observed, such as someone’s visual appearance, the clothing they wear, the music they listen to, and the food they eat. This level is the most surface and simplistic level of the different dimensions of culture. Second is the *Behavioral* level, which includes things like someone’s spoken language as well as their nonverbal communication, their family structure, their affiliations, and the way they define their roles in society. This level is more complex and reflects the values of the individual. Third and final is the *Symbolic* level, which includes things such as an individual’s religious beliefs, their values and morals, their customs, and their views of the world. This is the deepest and most complex level of culture and is often the key to how an individual defines himself or herself. It is this deep level of culture that is reflected in the values and beliefs component of the theoretical model. When values based on the sum total life experiences are viewed as causal conditions, one has the *sine qua non* of the impact of culture, or decisions and norms of actions.

Recommendations for Practice. Often, when attempting to understand the culture of others, people immediately begin at the concrete level, looking at surface level dimensions such as race, social class, gender, and sexual orientation (Hidalgo, 1993). Thus, it is very easy to make judgments and define someone based on these more obvious characteristics. This is often how people have defined cultural differences within our

society, including our school systems. When defining students and families in these terms we may be overlooking those critical aspects of their cultures that will aid us in creating more effective partnerships during the process of planning for the future lives of their children.

The knowledge that parents' cultural values and beliefs, which come from their deepest level of culture, lead to the expectations and goals that they hold for their children with significant disabilities is important because of its implications for transition services. It is recommended that professionals who provide transition services to children with disabilities acquire an understanding of parents' deepest cultural values and beliefs and make the connection between these values and beliefs and the post-school expectations and goals they hold for their children. Thus, service providers need to develop cultural competence. Cultural competence refers to "the ability to think, feel, and act in ways that acknowledge, respect, and build upon ethnic, cultural, and linguistic diversity" (Lynch & Hanson, 1993, p. 50). As previously mentioned in Chapter II, this requires four actions on the part of the professional.

First, service providers must become aware of their own cultural values, expectations, and perspectives of transition regarding employment, education, social and leisure integration, and independent living. This self-awareness can be achieved by examining one's own values and beliefs with the aim to realize that these are based on cultural background and experience rather than the ultimate reality for every person. This awareness process can aid in becoming conscious of their stereotypes, biases, and prejudices, which may be followed by changes in actions and interactions on the part of the professional (Chamberlain, 2005; Sparks, 2008).

Second, service providers must learn about the families in the community they work. This can be accomplished by getting involved in community organizations and/or events that focus on diversity, interacting with individuals with diverse cultural backgrounds, and developing relationships with these people. These interactions might lead to opportunities to engage in others' cultural traditions, celebrations, and rituals. There are also things that professionals can do on their own to increase their awareness of cultural differences that exist within families they support. For example, they can participate in courses or trainings focusing on diversity awareness and competence; they can read and preview publications and presentations that focus on people from diverse cultural backgrounds; and they can visit other countries to immerse themselves in different cultural societies and practices (Turnbull, Turnbull, & Wehmeyer, 2010).

Third, service providers must acknowledge and respect cultural differences. Becoming aware of cultural differences can provide an understanding of how cultural beliefs and values influence parental interpretations of services their children with disabilities receive in school. This awareness "is an important ingredient in efforts to work effectively with families of students with disabilities in transition. Above all, professionals should make every effort to respect a family's point of view, even if they are not in agreement" (Steere et al., 2007, p. 66).

Fourth and finally, mutual goals between families and service providers must be developed. This can only be accomplished by working in an equitable partnership with these families, gaining an understanding of their expectations and goals for their child, and providing them with the knowledge and resources to help support them in their journey.

Besides professionals already working in the field, teacher preparation programs needs to take into account the need to prepare future service providers with the understanding and skills needed to work with a diverse population of students. Considering the power of values and beliefs as causal conditions, this can be accomplished by requiring them to take coursework that addresses how to learn about and be responsive to these values and beliefs of people from different cultures. This will provide new teachers with the necessary tools to work more effectively with families who are culturally and linguistically diverse, as well as become more culturally sensitive to the children within their classrooms.

Effects of the Phenomenon

The participants' cultural values and beliefs based on their past experiences and their views of disability resulted in one main phenomenon. This central phenomenon was the idea that parents' perspectives of the transition process for their children with significant disabilities were based on viewing their children as reflections or extensions of themselves, and as deserving the same goals as they hold for themselves. Thus, this phenomenon provided an explanation for the expectations parents had for the future lives of their children with significant disabilities, as well as the expectations they had for the services being provided to their children and the transition process.

Three *expectations* characterized how parents' viewed their children in relation to themselves. First, all parents had *goals and dreams* for the future lives of their sons or daughters that reflected the goals and dreams that they had for themselves. As they desired for themselves, all participants had one ultimate goal for their children: happiness. Second, parents desired their children to be *reflections* of themselves. This

was evident through the desire for their children to be involved in the same activities as they were, to share their same values and beliefs, and to have a “typical life” based on how they defined a “typical life.” Third and finally, parents desired their children to be *extensions* of themselves. This was evident through their desire for their children to have more than they did and to experience more than they did.

Recommendations for Practice. It has been thought that parental expectations and goals for the future lives of their children are formed by the services provided through the school system (Brown et al., 1989; Lehman & Roberto, 1996; Sailor, 1991). In fact, in the past it was thought that families entered this transition process with a clean slate that service providers could fill up with their vast knowledge, resources, ideas, and goals, thus creating the ideal adult life for their students. However, considering the findings of this study, parental expectations and goals for their children’s future lives are not developed from the school’s mandated transition services and planning process, but in fact parents have expectations and goals for their children’s lives based on their own cultural values and beliefs. Families do not enter into this process with a clean slate for professionals to fill but in fact have goals, dreams, wishes, expectations, and plans of their own for their children’s lives and the services they receive through the school system. Although school personnel and educational practices can influence parental expectations, they can only serve as a support or a barrier to their expectations and goals. This is a shift in thinking from one where school procedures and services control what families envision for their children’s futures, to one where students and their families determine their own post-school outcomes.

Alternative planning approaches have been developed that facilitate a more active role of families and students in the transition process. Person-centered planning strategies

. . . are based on the assumptions that individuals with disabilities have rights to a community presence and community participation and that they be considered competent, have valued community roles, and have choices about both everyday matters and those that will have a greater life impact” (McDonnell & Nelson, 2010, p. 127).

Another approach, family-centered planning, focuses on family members of children with disabilities being actively involved in making decisions that meet the needs of the family as a whole (Saleebey, 1996). However, for individuals with more significant disabilities, there is a need to combine these two approaches to maximize ultimate planning success.

It is recommended that the Person-Family Interdependent Planning Approach, suggested by Kim and Turnbull (2004), in which cultural values and beliefs of the family are taken into account, be utilized for successful transition planning with culturally diverse families. This approach is based on five fundamental ideas. First, family members of students with disabilities are directly affected by their transition out of the school system and into the adult world. Thus, it is important to include family members in planning for the post-school lives of their children. Second, students with significant disabilities have a right to make choices regarding their own lives, often defined as self-determination. However, according to Wehmeyer, Palmer, Agran, Mithaug, and Martin (2000), “people misinterpret self-determination as meaning that you do everything yourself” (p. 445). Instead, self-determination should be seen as a means for “making things happen, without implying that he or she should be solely responsible for goal implementation or provision of supports needed” (McGuire, 2010, p. 102). Thus, the use of self-determination does not eliminate the need for family involvement and influence

on the planning process. Third, no one is completely competent in all areas of life, thus we all seek input from others including our family members on important life decisions. Therefore, it is important to solicit family input as to their expectations for the future lives of their children.

Fourth, when planning for the future life of a student with significant disabilities, the needs of the family and the child should be considered. Thus, planning should incorporate parents' input when identifying post-school service options and goals. Fifth and finally, transition procedures and programs that provide several different service delivery models need to be implemented. Traditional service delivery models currently available to adults with significant disabilities and their families might not meet student needs or parental expectations. Thus, these students are in jeopardy of remaining isolated from their communities, lacking supports and services needed to access and participate in adult living environments.

Effects of the Intervening Conditions

Intervening conditions are indirect factors that influence parental expectations for the future lives of their children with significant disabilities. As previously described, parents' expectations for their children are based on their cultural beliefs and values which have developed from past experiences and views of disability. Changes to these expectations occurred when these indirect factors either sustained parents' core beliefs and values, or served as barriers to their belief systems. Indirect factors such as negative experiences within different systems, lack of resources, and lack of opportunities were identified by participants as having an influence on the expectations they had for their children. Because of these conditions, participants felt the need to take certain actions and

to interact in certain ways to overcome barriers, to find acceptance within their current circumstances, and to eventually try and reach the goals they had set for their son or daughter.

During these interviews, participants shared experiences and barriers that they had when helping their children with significant disabilities reach the expectations for their future lives. These negative experiences included such things as: negative school events and attitudes of professionals, low expectations from professionals, and dealing with the bureaucratic procedures of special education. The identified barriers included such things as: lack of qualified staff, limited post-school options and resources, and lack of guaranteed services for the future. Along with negative experiences and existing barriers, participants also identified lack of opportunities available for their children to participate in employment, post-secondary education, independent and supported living situations, and recreation and leisure activities. Based on the reports from these parents and other experts in this field, this lack of opportunities is evident through the fact that most post-school services and opportunities available to individuals with significant disabilities have changed very little over the last twenty-plus years.

Besides limited opportunities for employment, participants reported that work experiences available to their children were low paying, only part-time, only available in segregated settings designated for individuals with severe disabilities, and tended to focus solely on repetitive and demeaning tasks. Several post-secondary education programs have started to emerge over the last several years for students with significant disabilities. Unfortunately, because this is a new trend and/or because of the lack of knowledge of professionals, post-secondary education programs were not even presented as an option.

Similar to employment and post-secondary education opportunities, independent or supported living options are also lacking. Despite the fact that most living options remain primarily segregated, these families must also have their children on a waiting list for years just to be considered for these services. If families are lucky enough to have these services available for their children, often other issues accompany having a loved one with a significant disability living outside the family home, such as being taken advantage of by someone in a position of trust. Finally, when it comes to recreational and social activities for their children, opportunities are also limited. Most activities available are, of course, segregated activities. Along with being segregated from people without disabilities, participants also reported segregation according to ability levels within the segregated activities themselves and a requirement for families to provide a support person to accompany their children to the activities, thus forcing many of them from even being able to participate in the segregated activities.

These negative experiences, identified barriers, and lack of opportunities likely exist for the majority of families who have children with significant disabilities. However, experiences and barriers such as these may intensify for families that are culturally diverse based on several different factors, such as: acculturation to American society, education level, family income, geographic location, and social class.

Recommendations for Practice. The tragedy of the foregoing experiences, lack of resources, and limited opportunities is that all of these are situations and supports that can be controlled by the systems within which services are being provided. Often professionals meet with family members of children with disabilities and explain to them what they think they should understand about this process and the services they should be

receiving. Well intentioned professionals often offend families by expressing goals and concerns they have for these families' children, rather than listening to the goals and concerns of the families.

How often do we attempt to build partnerships with families who feel that assumptions have been made about them by other professionals who have shown a lack of respect or blame for the parent, as well as undervalued the parent's expertise about his or her own child? (McDonnell & Nelson, 2010, p. 134).

Parent-professional relationships have been emphasized and regulated by law for many years now. Unfortunately, based on practices in the field, "the law is relatively powerless to foster partnerships. It is up to people to breathe life into the written law" (Turnbull, Turnbull et al., 2006, p. 140). Many families of children with significant disabilities, including those who are culturally and linguistically diverse, have reported years of negative experiences and attitudes (deFur et al., 2001; Geenen et al., 2003; Kim & Morningstar, 2005; Salembier & Furney, 1997). These negative experiences make it difficult for families to trust those providing services to their children.

It is recommended that practices that foster trust, build rapport, and strengthen relationships between families and professionals be implemented. Several practices align with this recommendation, such as (a) establishing effective communication practices; (b) supporting families beyond the IEP goals; (c) establishing equality within the relationship; (d) incorporating opportunities to learn from one another, which can increase the knowledge and skills of families and professionals; and (e) building trust and respect among families and their children's service providers.

(Blue-Banning et al., 2002; Smith et al., 2006; Turnbull, Turnbull et al., 2006).

Besides experiencing negative events and attitudes, families of individuals with significant disabilities, including those who are culturally diverse, often report lack of

opportunities available to their loved ones once they exit the school system. One reason for this might be the families' lack of knowledge of possible post-school options (Chambers, Hughes, & Carter, 2004). Another explanation might be the fact that the post-school options that are available do not align with family goals and expectations for their children. Either way, transition service providers must help all families see the possibilities that are and might be available to their children in the future. To do this, professionals must first become aware of available options themselves. Preparation of transition service providers has been recognized as a critical factor in increasing positive post-school outcomes of these students (Blalock et al., 2003; Kohler & Greene, 2004). Unfortunately, pre-service and in-service professional development opportunities are lacking in this area (Benitez, Morningstar, & Frey, 2008; Kleinhammer-Tramill, Geiger, & Morningstar, 2003).

In order to provide families with the necessary information regarding available post-school services and opportunities, service providers cannot simply hand over a stack of pamphlets. Instead, information must be shared through multiple means and interactions with families that occur over time. Information exchange can occur during planning meetings, trainings and workshops, and events such as community agency resource fairs. It is also important to emphasize that educating the family is not the primary purpose but reciprocal sharing of information and resources is key especially when working with families from diverse cultural backgrounds (Hanley-Maxwell et al., 1998).

There is increasing evidence that inclusive special education programs are as effective or more effective than segregated programs (Fisher, Sax, & Pumpian, 1999;

Hunt & McDonnell, 2007; Wehmeyer & Sailor, 2004). Hence, students with disabilities are being included in general education environments more. Yet adult service models continue to be predominately segregated. This creates a dilemma for families wishing for more inclusive services (Steere et al., 2007). In the remainder of this section, these issues will be illustrated in relationship to employment, post-secondary education, independent or supported living, and recreational/social activities.

First, employment options for individuals with significant disabilities have traditionally been sheltered workshops and day programs. However, supported employment within integrated settings is now viewed as a better option. Yet, despite success of supported employment, the continued use of facility-based programs persists. Unfortunately, many transition service providers, adult agency professionals, and families assume that segregated programs are the only option for students with more significant disabilities. It is recommended that post-school goals and referrals to these programs be eliminated (Grigal et al., 2011) and funding used to support these types of programs be used to support individuals with significant disabilities in more integrated employment settings.

Second, post-secondary education options for individuals with significant disabilities continue to emerge (Doyle, 2003; Grigal et al., 2005; Hafner et al., 2011). However, many of these students are not being prepared for this option during their programs in the public school system. “It is possible that few transition coordinators, general and special educators, higher education personnel, personnel from adult service agencies, and students and families know about these options” (Grigal et al., 2011, p. 14). It is recommended that transition service providers and post-secondary education

personnel seek professional development to gain knowledge for transitioning students with significant disabilities into these types of postsecondary experiences (Grigal & Hart, 2010). The most recent amendments to the Higher Education Opportunities Act of 2008 provides a description of transition programs for students with significant disabilities that focus on variability of post-secondary education services. Funding has become available to create model programs for the purpose of developing and expanding these types of programs so that they are more readily available to these students. Thus, it is recommended that the Higher Education Opportunities Act of 2008 and the upcoming reauthorization of IDEA align to include provisions that ensure access to post-secondary education opportunities for students with more significant disabilities (Grigal et al., 2011).

Third, post-school living options have been limited to segregated institutions and group homes. Concerns about these types of living situations have been identified to include such things as: limited choice and control, no prediction in living arrangements, and choices and desires of individuals with disabilities are secondary to those of the adult service providers. Because of these concerns as well as others identified by the participants of this study, it is recommended that a supported living approach be utilized that emphasizes the need for individuals and their families to have more control and choice over post-school living arrangements. Opportunities to make connections and develop relationships with the people in their communities are needed in order to develop natural supports that can serve as a long term support system (Steere et al., 2007). Again, it is recommended that post-school goals and referrals to agency-operated segregated residential facilities be eliminated and funding used to support these types of placement

be used to support individuals with significant disabilities in more integrated living environments.

Fourth and finally, recreational activities for students with significant disabilities need to be improved. Some authors have discussed the need for inclusive social and leisure opportunities to become available to these students (Moon, 1994; Schleien, Green, & Stone, 2003). For most people, relationships with family and friends are critical to their happiness and quality of life. “Clearly, engagement in recreation and leisure activities is one important avenue to the development of potential friendship” (Steere et al., 2007, p. 288). Thus, assurance of these opportunities is a critical element that needs to be put into place during transition planning for students with significant disabilities.

Effects of the Context

Contextual conditions were properties that existed when participants were in the process of developing a vision and transition plan for the future lives of their children with significant disabilities. The four contextual conditions that emerged from these data were: levels of collaboration, violations of individualized programming, failure to acknowledge wishes of family members, and on-going family issues. All of the identified contextual conditions caused families to take actions and/or engage in interactions to deal with these issues or challenges, sometimes diverting their attention from their original path toward goals for their children.

First, school personnel often discouraged the building of collaborative relationships by participating in practices that discouraged parental involvement. These practices included such things as: using special education jargon, talking about their children in negative ways, and not including families as equal members on the IEP team.

Next, these children often received services that did not meet their individual needs. Practices such as having the same IEP goals for all children, having narrowly focused transition services and post-school goals, providing pre-established center-based school programs, and the over usage of paraprofessionals were all practices that led to the violation of individualized programming for these students. Lastly, oftentimes services provided to these children and the plans put into place for their transition did not take into account the wishes of their families. This was evident by the discrepancies between parental expectations of services and actual services being provided, IEP goals and services based on school expectations, and post-school plans based on traditional options.

Challenges can also develop within the family unit itself, independent from the school or their services. On-going family issues were identified as family structures or happenings within the family unit that had an impact on the family as a whole. Most of these issues influenced the amount of support, financial resources, and time available to the families which in turn caused participants to take specific actions in order to deal with this lack of resources. Some participants also identified challenges in their lives that caused them enormous amounts of stress. For these participants, the feelings of urgency to make sure plans were in place for the care and support for their children's future lives were much greater.

Recommendations for Practice. The findings of this study suggest that families with differing cultural values and goals for their children continue to be put into passive roles when it comes to working with professionals to establish programs and plans for their children with significant disabilities. As previously stated, students and their families need to become the guiding force in planning for their children's future lives. In

order for parents to take on this role, professionals must give up control they have become accustomed to having.

Along with establishing collaborative parent-professional partnerships with families, the need to provide more individualized programming to students with significant disabilities is warranted. The very fact that pre-established programs for students with more significant disabilities exist in our school systems creates the option for service providers to implement instructional methods, adaptations, program planning, and support services in a non-individualized manner. Often a parent of a child with a significant disability will take that child to enroll in school; the school will assign him/her to the teacher, program, or classroom where all other children with his/her disability label are enrolled; and every student in that classroom or program will receive the same or very similar services, including the same adaptations, the same goals on their IEPs, the same post-school goals, and of course, every student in the program will be assigned a paraprofessional for support. There is no room for individualization in this type of pre-established programming, let alone, room for consideration of cultural diversity. This type of standardized “individualized” programming must be eliminated. It is recommended that school districts seriously consider how post-school outcomes are affected by this “one-size fits all” type of programming, especially for families with different cultural backgrounds.

Certainly, while the theoretical model delineated contextual conditions that are related to schools, as previously described, there were also challenges that occurred within families. Families might experience challenges such as substance abuse, health problems, domestic violence, or poverty. These types of challenges can deter families

from participating and supporting their children through the transition process. In unique situations such as these, professionals must ensure trusting and supportive relationships with these families. When there are different cultural values, professionals must be especially careful to honor how culture defines the communication of these personal family issues.

Effects of the Actions/Interactions

Actions and/or interactions were specific strategies participants used to try and achieve the expectations they held for their children's future, given the barriers they faced, the fewer opportunities they were provided, and the limitations in resources. Each of these actions/ interactions had specific outcomes, which may or may not have contributed to their goal of a successful life for their children. As noted previously the goals these families held for their children were grounded in how they defined success for themselves, which reflected cultural values and beliefs about life and about disability.

Participants reported pushing for better educational experiences for their children throughout their time in the school system. They pushed for these better educational experiences to help their children reach the goals and expectations they had for their future lives. Parents also admitted to accepting less than desirable services generally after they experienced some kind of negative interaction or event with school personnel or after fighting without success for something they wanted for their children. Parents reported searching for post-school resources on their own when the school did not provide them with resources and/or the resources provided were not sufficient for meeting their needs and expectations. Parents also described their actions of going through the motions to get through meaningless legal requirements when reacting to

negative experiences taking place at the school, events taking place in their own lives, and when they felt like it was too late to do anything to improve their current circumstances with the school or their children's services. Finally, some participants felt like one of the biggest barriers to their children reaching the expectations and goals they had for them was the idea that something about their children needed to be fixed in order for them to be successful members of society. With this realization participants described their process of accepting their children's disabilities as something that did not need to be fixed. In turn, this mindset influenced how they approached the process of planning and preparing for the future.

Recommendations for Practice. While families coming from any culture will be faced with these same issues, perhaps families from minority cultures may not always have effective strategies for overcoming these impediments that members of the dominant culture might have. It is recommended that professionals learn to recognize and value goals originating out of different cultural experiences and honor the actions that families take to try and achieve their goals in the face of these barriers.

In addition, helpful resources should be made available for families to use. For example, helping parents identify people who can provide support to their family such as extended family members and/or friends. Furthermore, families might also be able to identify resources within their communities or neighborhoods that can assist them in ways that professionals cannot, such as members of the church they attend or people in their neighborhood. As previously discussed, it is important for service providers to help families become aware of more structured resources available to provide support and services to individuals with significant disabilities. For example, providing parents with

contact information of available sources of support, inviting outside resources to meetings with the family, creating family support groups where parents can connect with other families going through similar processes, and developing trainings for families that focus on adult services and transition procedures.

Effects of the Consequences

There were two specific consequences produced by the actions/interactions taken by the participants in this study. First, feelings of empowerment were felt by participants, defined as feelings of being in control and feelings of security for the future. Second, there were feelings of defeat, defined as unsuccessful endings to challenges and struggles or the feelings that accompany an experience of being thwarted in obtaining goals or eliminating something expected. Thus, feelings of defeat are essentially the opposite of feelings of empowerment.

These outcomes illustrate the general feelings these participants experienced as they went through the process of planning and preparing for the future lives of their children with significant disabilities. Although some of the actions and/or interactions taken by participants led to them feeling more in control and secure for the future, these same actions and/or interactions many times led participants to also feel fearful, dissatisfied, and isolated.

Recommendations for Practice. In order to increase parental empowerment and decrease feelings of defeat in culturally diverse families, services providers must implement practices that will lead to this end. People who are empowered take action in an attempt to gain more control over a situation or to satisfy a certain want or need (Akey, Marquis, & Ross, 2000; Turnbull, Blue-Banning, & Pereira, 2000).

Empowerment is the opposite of defeat, the feeling of being stuck in a challenging situation and not having the ability or motivation to overcome it. As service providers develop partnerships with families, they must help them to foster their empowerment. “People tend to avoid activities and situations in which they believe they cannot succeed” (Turnbull, Turnbull et al., 2006, p. 153). Families will be more likely to embrace the transition process if they experience shared expectations and feel valued by the process.

One way to empower parents is by encouraging them to believe in their own abilities and to provide them with opportunities to apply their efforts (Scorgie, Wilgosh, & McDonald, 1999). In order to guarantee the values and goals of families are honored, families must be actively engaged in the transition planning process. Thus, transition service providers must be adequately trained in order to implement interventions that will facilitate parental understanding of the transition process (Landmark et al., 2007).

Future Research

The transition of students with disabilities from the school system to adulthood has emerged as one of the most important areas of service (Kohler & Field, 2003; Landmark et al., 2010). Due to continued findings that show poor post-school outcomes for students with disabilities, the focus on these services has intensified (Johnson et al., 2002; Wagner et al., 2005). Despite this increased focus, not much is known regarding cultural differences associated with the transition to adulthood (Kim & Morningstar, 2005; Trainor et al., 2008). As this study has shown parents representing different and diverse cultures acquire deep and abiding values from their life experiences and their experiences with disabilities that impact how they express themselves in the lives of their children.

In spite of existing data showing demographic changes in the school population, much of the research investigating transition services for families from different and diverse cultures has not addressed how their values and beliefs determine the formation of goals for their children or how these goals are thwarted by the context and conditions of schools. In order to learn more about the expectations and experiences of culturally diverse parents of children with significant disabilities, two types of data are needed. First, more quantitative data are needed using large data sets that include families from different culturally and linguistically diverse backgrounds that investigate how cultural experience, family goals, and school context interact in transition decision making processes. Second, additional research is also needed in order to collect in-depth, rich descriptive data leading to a better understanding of families who are culturally diverse in relation to these same processes.

Although, the theoretical model presented here was built on the experiences of the five families participating in this study, there exists the possibility that it can be fruitfully applied to the study of many other cultures, including the dominant cultures across different societies. Additional research is also needed to verify the usefulness of this model with families from different social classes, with different educational levels, and with families whose primary language is different than English.

In a related vein, there exists within the system of special education certain “ideals, values, and assumptions about [education and students with disabilities] that are widely shared among [service providers] and that guide specific [educational practices for these students]” (Brislin, 1993, p. 4). This culture of special education can be viewed as a dominant culture that impacts the views of other cultures including those of people

of color and representing different value systems. Because of this culture, often times service providers can find themselves caught implementing practices based on tradition and ease rather than implementing new and innovative ideas acquired during training or professional development. A research concern then, is how to help service providers be able to look objectively at special education and not be controlled by it when working with families such as those represented in this study.

Limitations

This study includes a number of limitations typically associated with qualitative research. Self-reporting served as the primary source of data in this study, thus the very nature of the interview process had the potential to create the first of these limitations. The presence of the researcher during the process of gathering data can influence participant responses due to their unwillingness to discuss personal and sensitive information and their perceived need to express information that aligns with the views of the researcher. Additionally, self-reporting is dependent upon participants' ability to recall events and articulate their experiences accurately. In order to address this possible limitation, participants in this study were offered the opportunity to read and respond to the transcripts and analysis of their individual interviews.

Another limitation associated with qualitative research is the difficulty that exists when attempting to generalize the findings to other situations. Taking into consideration the fact that the sample was from one region in the United States, the findings of this study may not apply to individuals who are in similar situations in other areas. Although different cultural backgrounds were represented in this study, perspectives gathered from participants may not represent the same perspectives of other parents with similar cultural

backgrounds who are from different social classes, who have different educational levels, and whose primary language is not English.

Despite these limitations, the usefulness of this study lies in the ability of readers to compare the stories of these participants with the stories grounded in their own experiences. Thus, transferability is dependent on readers' interpretation of the findings and their acceptance of these findings in relation to their own situations.

Conclusions

The purpose of this study was to investigate culturally diverse parental perspectives of transition services being provided to their children with significant disabilities. Current research suggests poor post-school outcomes for this population of students. Studies have reported less involvement from parents who are culturally diverse in transition related activities. Existing literature has failed to comprehensively address the experiences and perceptions of parents that represent both minority cultures and significant disabilities in the transition processes.

A logic model was developed to help organize participants' perspectives of the transition process and services being provided to their children. This visual representation of data serves as a basis for a deeper understanding of experiences and challenges these families are faced with during this period of their children's lives and calls for future research in this area as well as reform within current educational and adult agency practices. The major findings of this research and their implications for practice have been summarized in Table 8.

Table 8

Major Findings and Implications for Practice

Major Findings	Implications for Practice
1. Cultural values and beliefs influence parents' definition of a successful life, thus influencing expectations and goals for their children.	<p>-Professionals who provide transition services must develop cultural competence.</p> <p>-Pre-service programs must prepare future service providers with understanding and skills to work effectively with diverse students and families.</p>
2. Shift from school procedures and services controlling families' visions for the future to students and their families determining their own post-school outcomes.	-Implement transition planning processes that ensure maximum family participation (i.e., Person-Family Interdependent Planning Approach)
3. Indirect factors, such as negative experiences, lack of resources, and lack of opportunities, create barriers to parental expectations.	-Reform post-school services and supports to better meet the needs and desires of diverse families.
4. Service delivery models for students with significant disabilities encourage violations of individualized programming mandates.	-Elimination of pre-established programs, IEPs, and services based on disability labels.
5. Family challenges have significant influence on ability to function and lead to support needs reaching beyond typical supports provided.	-Take into account individual characteristics of families when developing working relationships and supports
6. Actions/interactions taken by parents when trying to achieve expectations for their children's future lives lead to feelings of empowerment and/or feelings of defeat.	<p>-Implement practices that increase empowerment and decrease feelings of defeat by encouraging families to take initiative and believe in their own abilities.</p> <p>-Provide families with opportunities and supports to apply their efforts.</p>

These findings are important to several groups, including school transition personnel, special education teachers, school administrators, parents of children with disabilities, and teacher educators. Based on the experiences of these families and the recognition of the importance of their involvement in the transition process, the information gained from this study provides information about challenges facing these families during the process of transition. Through a better understanding of the experiences of these culturally diverse families during transition, strategies that enhance parental involvement and improve transition outcomes can be implemented.

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APPENDIX A
INSTITUTIONAL REVIEW BOARD

UNIVERSITY of
NORTHERN COLORADO

 University of Northern Colorado
INSTITUTIONAL REVIEW BOARD
 Application for Exemption from IRB Review

Section I - Statement of Problem/Research Questions

When looking at the post-school outcomes for students with disabilities who are culturally and linguistically diverse, discrepancies become apparent. These students tend to have worse post-school outcomes than even those of their peers with disabilities who are not from a culturally diverse background (Geenen, Powers, & Lopez-Vasquez, 2001). The most recent statistics continue to show lower employment rates, wages, and enrollment in postsecondary education programs for students with disabilities who are racially and ethnically diverse when compared to their Caucasian peers (Wagner, Newman, Cameto, & Levine, 2005). Continued post-school outcomes such as these indicate that professionals in the field might be implementing a one size fits all philosophy when providing transition services to their students.

The purpose of this study is to address, via qualitative methodologies, parental perspectives on transition services that are being provided to their children with significant disabilities who are also culturally and linguistically diverse. The need for this study is based on three existing circumstances. First, the National Longitudinal Transition Study's (NLTS-2) most recent findings continue to show negative post-school outcomes for this population of students, and it acknowledges parent expectations as a powerful predictor of positive post-school outcomes. Second, studies have reported comparatively less involvement from parents from ethnically and culturally diverse backgrounds in transition related activities (Geenen et al., 2001; Garriott et al., 2000; Salembier & Furney, 1997). Third and finally, as previously noted, the existing literature has failed to comprehensively address the experiences and perceptions of parents that represent both minority cultures and significant disabilities in the transition processes.

Guiding Questions

The primary research question that will be addressed in this study is: What are the experiences and perspectives of parents who are culturally and linguistically diverse on the transition services being provided to their children with significant disabilities?

The guiding questions that will be used to help answer this question are:

- Q1 What are the expectations of parents who are culturally and linguistically diverse regarding the post-school life of their children with significant disabilities?
- Q2 What stories do parents who are culturally and linguistically diverse tell that illustrate their feelings and experiences with the transition process of their children with significant disabilities?

- Q3 Are there concerns or barriers facing parents who are culturally and linguistically diverse regarding their involvement in the transition process of their children with significant disabilities?
- Q4 In relation to program documentation (e.g. IEP/ITP), are there discrepancies between parental expectations and parental descriptions of their children's service needs when these are compared with the expectations and the services provided by schools?

Section II - Procedure

Participants

The families that will be used in this study will be selected through a purposeful sampling procedure to ensure that they are qualified to provide the necessary perspectives. For the purpose of this study, possible participants will primarily be chosen through a successive sampling process referred to as theoretical sampling. This process will begin with the selection of an initial family that is chosen for its relevance to the study. The data gathered from this family will lead to the selection of the next family and so on. To some extent, this process will rely on convenient sampling which yields a sample based on the researcher's resources such as time, money, location, availability of sites or respondents, and so on. However, every effort will be made to employ strategies from theoretical sampling so that an adequate theoretical model will emerge from this research. Three primary selection criteria will be used for the identification of participants for this study. First, participants must be parents of students who have significant disabilities. Second, they must be from a culturally and linguistically diverse background. Third and finally, their daughters and sons must be between the ages of 16 and 21 years and must be receiving transition services from a school district or educational entity at the time of this study.

Setting

It is expected that some parents will choose to be interviewed in their home and others might want to be interviewed at a more public place. However, it is anticipated that interviews conducted in the home will add to the richness of the data because this represents the most natural environment. Hence, this will be my first choice of settings for these interviews.

Data Collection Procedures

After the study is approved by the institutional review board, a pool of potential participants will be developed using contacts from previous studies, contacts known by parent advocates, contacts involved in parent support groups such as PEAK Parent Organization and The ARC of Colorado, and contacts suggested by other potential participants.

Contact Visits

Once an individual has expressed interest in participating in the study, a contact visit will be arranged. Consistent with the recommendations of Seidman (2006), these

contact visits will be preliminary to the actual beginning of the study. These initial contact visits are designed to aid in selecting participants and help build a foundation for the interview relationship (Seidman, 2006). If potential participants do not want to meet face-to-face for this initial contact it can be completed over the phone or by email.

During contact visits groundwork will be laid for the mutual respect needed during the data collection phase of this study. The initial contact visits might also provide an opportunity to explore the homes or work environments of potential participants before having to conduct the actual interview (Seidman, 2006). During this contact, potential participants will also be informed of the in-depth interview process and the need for the researcher to review relevant documentation, including a copy of their child's IEP or Individual Transition Plan (ITP). Finally, this initial contact will serve as a forum for going over information about audio-taping, confidentiality, and the informed consent which will be signed at this time (Corbin & Morse, 2003).

A database of potential participants will be developed. Information will include such items as the participants' address, telephone numbers, email address, and times when they will be available to talk or times to avoid will be collected during the contact visit. Based on these initial contacts, those potential participants who seem most suitable to the topic of the study will be selected, and the first of these families will be invited to participate. Follow-up letters will be sent to all remaining potential participants, thanking them and indicating to them whether or not they have been selected to participate in this study. So that replacement participants can be identified, the database will continue to be maintained as the study proceeds.

Interviews

The primary mode of data collection in this study will be tape-recorded in-depth, semi-structured interviews using a person-to-person approach. For the selected participant families, there will be a series of three separate interviews. Each interview should last approximately 90 minutes in length. In order to allow the participant time to reflect on the previous interview but not enough time to lose what they have already talked about, interviews will be spaced three days to one week apart. This same process will continue across all participants.

After each interview, I will listen to and transcribe the raw data from the audio tapes verbatim, and then provide a copy of the transcript to that participant upon my next visit. I will store all data including my field journal, memos, transcriptions, and other observational notes on a computer, each case study in their own locked file. Although it is anticipated that three interviews will be sufficient, some additional follow-up contacts may be necessary. Upon completion of the interviews, participants will be compensated \$90 for their time. However, potential participants will not be compensated for the initial contact visit.

Fieldnotes & Memos

In this study I will also make fieldnotes while conducting interviews and as a process of reflection on the interview process. These fieldnotes will cover such things as

the transcript of conversations and interviews, audiotapes, copies of IEP/ITP documents, and research field journal or memos. Written accounts, or memos, of the analysis or directions for the analysis including progress of the study, feelings of the researcher, the researcher's thoughts regarding the study, and future directions of the research process will be employed in this study. Along with memo writing, I will make a computer file for each participant that will contain interview transcripts, memos, my thoughts recorded following each interview, and any charts developed from the data analysis process.

Document Review

Each participant will be asked to provide a copy of their child's individual transition plan (ITP) to the researcher. ITPs will be reviewed and analyzed in order to determine the transition services being provided to each participant's child. The analysis of these documents will then be compared to the expectations of the parents to determine if there are any discrepancies between school services and parent expectations. Collection of this data is intended to answer the following research questions: In relation to program documentation (e.g. IEP/ITP), are there discrepancies between parental expectations and parental descriptions of their children's service needs when these are compared with the expectations and the services provided by schools?

Demographic Data

Demographic data will be collected on each participant in the study through the use of a questionnaire (see Appendix A). Participants will be given this demographic form to fill out at the time of the first interview. Data collected through this questionnaire will be used for descriptive purposes.

Section III – Disposition of Data

Prior to conducting the first interviews, participants will be assured of the confidentiality of their statements and will be informed of their right to withdraw from the study at any time. Participants will be required to sign a Human Subjects Consent Form prior to the interview (see Appendix B). Participants in the study will be asked to choose a pseudonym to be used during the interviews and on interview transcripts, thereby maximizing confidentiality. Only the researchers will know which participant goes with which pseudonym in case any follow-up contacts need to be conducted. After data analysis is complete, copies of print transcripts will be shredded, and only an electronic copy will be stored on the computer, which is password protected. Electronic copies will only be maintained for five years. Researchers' notes will also be kept electronically for a period of five years, and then, they will also be deleted. The research advisor will maintain consent forms for a period of one year. Results will be shared with participants upon request.

Section IV - Justification for Exemption

This study qualifies for exemption because participation is voluntary, and all participants will be adults. Participants will have the option of withdrawing from the study at any time. Furthermore, personal identification will not be used during the interviews or in the transcriptions. Subjects will also not be identified by geographical region. Thus, individuals will not be directly linked with their responses, and accidental

disclosure should not harm the participants. The researcher anticipates minimal or no risk to participants.

Section V – Documentation

Please refer to the attached appendices:

- a. Demographic Sheet (see Appendix A)
- b. Informed Consent (see Appendix B)
- c. Contact Visit Information Form (see Appendix C)
- d. Proposed Interview Script (see Appendix D)

STUDENT'S COPY

August 13, 2007

TO: Gary Heise
School of Sport and Exercise Science

FROM: SPARC

RE: Exempt Review of *Transition to Adulthood: Culturally Diverse Parental Perspectives*, submitted by Kara Halley (Research Advisor: Lewis Jackson)

The above proposal is being submitted to you for exemption review. When approved, return the proposal to Sherry May in SPARC.

I recommend approval.

Gary D. Heise 9/13/2007
Signature of Co-Chair Date

The above referenced prospectus has been reviewed for compliance with HHS guidelines for ethical principles in human subjects research. The decision of the Institutional Review Board is that the project is exempt from further review.

IT IS THE ADVISOR'S RESPONSIBILITY TO NOTIFY THE STUDENT OF THIS STATUS.

Comments:

emailed 9-4-07
- Location of Data at UNC for next 5 yrs?
- Consent revisions: risks/benefits; 2-pages; initial
- Only parents? stress "eff. time" not "below" Confid. from school?
Send revision

UNIVERSITY of
NORTHERN COLORADO

APPENDIX B

INFORMED CONSENT

Informed Consent for Participation in Research
University of Northern Colorado

Project Title: Transition to Adulthood for Students with Significant Disabilities:
Culturally Diverse Parent Perspectives

Researcher: Kara Halley, M. A., School of Special Education

Contact Information: phone #:

E-mail:

I am a doctoral student at the University of Northern Colorado and, I am interested in researching parents' perspectives on transition services that are being provided to their children with significant disabilities who are also culturally and linguistically diverse. Potential participants should be parents of students who have significant disabilities. They should be from a culturally diverse background and their daughters and sons should be between the ages of 16 and 21 years and should be receiving transition services from a school district at the time of this study.

Information will be collected mainly through face-to-face interviews. There will be a minimum of three separate interviews. Each interview will last about 90 minutes. Interviews will be spaced at least three days apart.

The purpose of these interviews is to find out about your experience with the process of your son or daughter leaving the school system and entering young adulthood. In order to ensure confidentiality, you will be asked to select a pseudonym to be used during the interviews. Interviews will be recorded, and the researcher will keep copies of the interview transcripts. All personal identifiers will be removed from the transcripts. Copies of interview transcripts and the study's results will be provided upon request. Participants will also be asked to provide a copy of their son's or daughter's Individual Education Plan (IEP). If you are selected for this study, you will be compensated for your time.

Data will be stored in a secure location that can only be accessed by the researcher. Furthermore, this information will be maintained for no more than five years, and then it will be destroyed. I do not foresee any unusual risks to participants as a result of this study as participation is voluntary and information disclosure is at the participant's discretion. As mentioned above, all necessary precautions will be taken to protect participant confidentiality. Participant names will not appear in any professional report regarding this research; only pseudonyms will be used. Participants will be compensated at the completion of this study.

Please feel free to contact me if you have any questions or concerns about this study. If you would like to participate in this study, read the passage below and sign and date this form. Thank you for assisting me in my study.

Sincerely,

Kara Halley

Participation is voluntary, and you may decide to withdraw at any time. Your decision will be respected and will not interfere with any benefits you may be entitled to. Having read the above and having had the opportunity to ask questions, please provide the requested information if you would like to participate in this research. Please retain a copy of this form for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the Sponsored Programs and Academic Research Center, Kepner Hall, University of Northern Colorado, Greeley, CO 80630; 970-351-1907. Please return this completed form to Kara Halley.

Participant's Signature

Date

APPENDIX C

CONTACT VISIT INFORMATION SHEET

CONTACT VISIT INFORMATION SHEET**Name(s):** _____**Address:** _____**City/State/ Zip Code:** _____**E-mail Address:** _____**Telephone Number:** _____**Preferred way to be contacted:** _____**1. Mother's Ethnicity:****(Check only ONE)**

- ☐ African American
☐ Asian or Pacific Islander
☐ Caucasian/White
☐ Hispanic/Latino
☐ Mixed Race/Ethnicity
☐ Native American/American Indian
☐ Other _____

2. Father's Ethnicity:**(Check only ONE)**

- ☐ African American
☐ Asian or Pacific Islander
☐ Caucasian/White
☐ Hispanic/Latino
☐ Mixed Race/Ethnicity
☐ Native American/American Indian
☐ Other _____

3. Primary Language Spoken in Home:

4. Primary Language of your son/daughter:

5. Total number of IEP meetings your have attended for your son/daughter during his/her time in high school? _____

6. Circle the number that best describes your desired involvement in your son/daughter's transition process:

(5 = Very Involved and 1 = Not involved at all)

5 4 3 2 1

7. Circle what best describes your satisfaction with your son/daughter's transition program:

Very Satisfied Neutral Dissatisfied Very Mixed
Satisfied Satisfied Neutral Dissatisfied Dissatisfied Feelings

8. Do you have access, or can you gain access, to your son or daughter's most current IEP/ITP?

YES or NO

9. Date and times you are usually available to meet:

	Mornings	Afternoons	Evenings
Mondays			
Tuesdays			
Wednesdays			
Thursdays			
Fridays			

APPENDIX D
DEMOGRAPHIC SHEET

DEMOGRAPHIC SHEET

Please provide the following information on your son/daughter in a transition program.

1. Current age/grade in school of son/daughter: _____

2. Gender of son/daughter:

_____ Male
_____ Female

3. Ethnicity of son/daughter: (Check only ONE)

_____ African American
_____ Asian or Pacific Islander
_____ Caucasian/White
_____ Hispanic/Latino
_____ Mixed Race/Ethnicity
_____ Native American/American Indian
_____ Other _____

4. Disability Type your son/daughter has:

PLEASE ONLY CHECK THE PRIMARY DISABILITY

_____ Learning Disability
_____ Speech or Language Impairment
_____ Mental Retardation
_____ Emotional Disability
_____ Multiple Disabilities
_____ Deaf/Hearing Impairments
_____ Orthopedic Impairments
_____ Blind/Visually Impaired
_____ Autism
_____ Deaf-blindness
_____ Traumatic Brain Injury
_____ Other Health Impairments _____

5. In what types of classes does your daughter/son participate in regular classrooms? (Check all that apply)

_____ Academics (e.g. Algebra, English, Science, Social Studies)
_____ Vocational Classes (e.g. Woodshop, Agriculture, Auto-shop, Business)
_____ Only Specials or Electives (e.g. P.E., Music, Art)
_____ None (Self-contained/Special Education Classes Only)

6. Does your daughter/son participate in work-study?☐ Yes☐ No**7. If Yes to Number 6, does your daughter/son receive graduation credits for participating in a work-study program?**☐ Yes☐ No**8. How does your daughter/son spend his/her free time?****(Check all that apply)**☐ Working☐ Studying☐ Hanging out with friends☐ Watching TV☐ Listening to music☐ Playing sports☐ Doing hobbies☐ Going to church or religious activities☐ Going to the mall or movies☐ Doing outdoor activities☐ Other: _____**9. Your daughter/son participates in:****(Check all that apply)**☐ IEP/Transition meetings☐ School supervised paid work in the community☐ School supervised volunteer work☐ In-school job☐ Job shadowing☐ Paid work on your own☐ Classes at a community college☐ Extracurricular activities☐ Vocational rehabilitation services☐ Community center board services☐ Other school-to-career activities: _____**10. Mother's Educational Background: (Highest degree earned) _____****11. Father's Educational Background: (Highest degree earned) _____**

12. Family income range:

☐ less than \$20,000 ☐ \$20,001-\$35,000 ☐ \$35,001-\$50,000
☐ \$50,001-\$75,000 ☐ \$75,001-\$99,000 ☐ \$100,000 or more

13. Number of people living in the family home _____
14. List the people living in the family home and their relationships to the student:
 (Use back of the form if you need more space)

15. Who is completing this form?

<input type="checkbox"/> mother	<input type="checkbox"/> brother	<input type="checkbox"/> guardian
<input type="checkbox"/> father	<input type="checkbox"/> grandmother	<input type="checkbox"/> other relative
<input type="checkbox"/> stepmother	<input type="checkbox"/> grandfather	<input type="checkbox"/> other (describe) _____
<input type="checkbox"/> stepfather	<input type="checkbox"/> aunt	
<input type="checkbox"/> sister	<input type="checkbox"/> uncle	