

UC San Diego

UC San Diego Electronic Theses and Dissertations

Title

Parent Perceptions of IEP Team Support Through Life-Course Transitions

Permalink

<https://escholarship.org/uc/item/0c76f9d3>

Author

Borrelli, Michelle Leigh

Publication Date

2022

Peer reviewed|Thesis/dissertation

UNIVERSITY OF CALIFORNIA SAN DIEGO

CALIFORNIA STATE UNIVERSITY SAN MARCOS

Parent Perceptions of IEP Team Support Through Life-Course Transitions

A dissertation submitted in partial satisfaction of the requirements for the degree of

Doctor of Education

in

Educational Leadership

by

Michelle Borrelli

Committee in Charge:

University of California San Diego

Professor Amanda Datnow, Chair

California State University, San Marcos

Professor Manuel Vargas

Professor Christiane Wood

2022

Copyright
Michelle Borrelli, 2022
All rights reserved.

The dissertation of Michelle Borrelli is approved, and it is acceptable in quality and form for publication on microfilm and electronically.

University of California San Diego
California State University San Marcos

2022

DEDICATION

To the women in my family before me
who have paved a way through their own work in social justice
so that I am able to live His truth
in service to those who may not be able to advocate for themselves.

“Each of you should use whatever gift you have received to serve others, as faithful stewards of God's grace in its various forms” (1 Peter 4:10)

To the families in this study and to all of the families I have had the honor of serving as an educator and advocate for social justice...You are my inspiration.

TABLE OF CONTENTS

Dissertation Approval Page	iii
Dedication	iv
Table of Contents	v
List of Figures	vii
Vita.....	viii
Abstract of the Dissertation	ix
Chapter 1: Introduction	1
Statement of the Problem.....	3
Purpose of the Study and Research Questions.....	4
Theoretical Frameworks	5
Significance.....	7
Organization of the Dissertation	8
Chapter 2: Review of the Literature.....	9
IEP/ITP Process and Stakeholder Roles in a Supportive IEP Team.....	12
Special Education Transition Frameworks and Theories	16
Building a Trustful and Supportive Team for Seamless Life-course Transitions	18
Chapter 3: Methodology	30
Review of Study Purpose.....	30
Research Design.....	31
Participants.....	32
Data Collection	35
Data Analysis	37
Limitations	41

Chapter 4: Results	43
Participant Profiles	43
Themes in Parent Perceptions of Supportive IEP Teams	53
COVID-19 Impacts on Transition and Family Quality of Life	55
Perceptions and Use of Coping Resources through Transitions	60
The Influence of Social and Academic Inclusion on Family Perceptions	64
Personal Development, Self-Determination, and Emotional Well-Being for Coping	68
Family Quality of Life Transition Planning.....	74
Rights, Well-Being, and Broken Trust in Family Perceptions of Team Support	82
Conclusion	86
Chapter 5: Discussion and Conclusion	87
Overview of the Problem and Purpose	87
Findings for Question 1	89
Findings for Question 2	92
Findings for Question 3	95
Implications for Future Research.....	98
Implications for Practice	99
Conclusion of the Study.....	104
References.....	105
Appendix A: Individual Initial Meeting Guide.....	113
Appendix B: Individual Interview Question Protocol	114
Appendix C: Research Consent Email and Form	116

LIST OF FIGURES

Figure 3.1 Special Education Familial Quality of Life through Transition Framework	38
--	----

VITA

- 2022 Doctor of Education, Educational Leadership, Joint Doctoral Program of University of California San Diego and California State University, San Marcos
- 2015 Master of Arts, Special Education, California State University, San Marcos
- 2004 Bachelor of Fine Arts, Visual Arts Studies, University of North Texas

PROFESSIONAL EXPERIENCE

- 2015-Present Education Specialist, Secondary Education, Adult Transition, San Marcos Unified School District, San Marcos, California
- 2012-2015 Instructional Assistant/Substitute Teacher, TERI, Incorporated, Oceanside, California
- 2007-2011 Elementary Teacher, Killeen Independent School District, Killeen, Texas
- 2004-2005 Elementary Art Teacher, Castleberry Independent School District, Fort Worth, Texas

FIELDS OF STUDY

Major Field: Education

Art Education
Elementary Education
Inclusive Education
Arts in Criminal Justice
Special Education
Art in Special Education
Organizational Leadership
Transition Theory
Quality of Life

ABSTRACT OF THE DISSERTATION

Parent Perceptions of IEP Team Support Through Life-Course Transitions

by

Michelle Borrelli

Doctor of Education in Educational Leadership

University of California San Diego, 2022
California State University, San Marcos, 2022

Professor Amanda Datnow, Chair

Parents of children with moderate to severe disabilities face greater obstacles and challenges in life compared to parents of typically developing children. Life-course transitions for students with disabilities, such as the imminent transition from public school systems to adult life, often elicits stress-induced emotions and perceptions in parents and students.

Individualized Education Programs (IEPs) and Individualized Transition Plans (ITPs) are collaboratively developed with input from the student, family, and many different professionals in the school systems. Ensuring students and families can access proper supports aligning with postsecondary goals for familial quality of life necessitates collaborative input from all

stakeholders. This study explored how parents of students with moderate to severe disabilities perceived the IEP/ITP teams and experiences with systems of support as their children transitioned from high school to post-secondary education. Quality of life domains and transition theory provided the conceptual lens to analyze the experiences and perceptions of 9 families with children who have moderate to severe disabilities and have transitioned their children to postsecondary education.

This phenomenological study took place during an unprecedented time of the global COVID-19 pandemic; the results illuminated unique stories of transition interwoven with the impacts of the pandemic. Findings from this study corroborate prior studies in transitions and quality of life of families of children with special needs. Self-determination, positive family outlook and perceptions of self, as well as culturally and familial sensitive strategies and supports appropriately initiated by IEP school teams, gleaned more seamless transition experiences for positive familial quality of life.

Keywords: special education, transition, secondary, post-secondary, IEP meetings, family support, Quality of Life (QoL)

“Deep, abiding sadness is my constant companion, as is unending joy.”

- Susan Slovia, mother of Teri Anne who was diagnosed with lissencephaly in 1992

(Klein & Schive, 2001).

Chapter 1: Introduction

Parents of children with moderate to severe disabilities face challenges far greater than parents of neurotypical children (Henninger & Taylor, 2014). Many of these parents may endure long days and nights, medical emergency scares, stresses relating to disabilities, and other obstacles requiring their full physical and mental alertness. However, the love between parent and child supersedes any challenges these parents go through on a daily basis.

The love parents feel for their child often may manifest as a sense of fear and anxiety around changes or transitions to new environments. Children with disabilities may fear a change in their environment which results in parental stress (Hassall et al., 2005). With this fear comes a higher need for emotional support for parents and children through transitions into new or different public service systems or placements (Klein & Schive, 2001). Diverse, extreme emotions bombard the lives of parents of children with disabilities, impacting transitions occurring within childhood, and young adulthood times of change for their child. Stress levels are high for families during transitions for students with disabilities, as unknown challenges could arise and cause an uncertain future for the entire family (Woodman, 2014). Families' concerns for the future can feel overwhelming when considering their child's adaptability being impacted by one or more disabilities. Finances, utilization, and understanding of services, and worry about the future, all place strain on the family (Leonard et al., 2016). To ease the stress of parenting a child with special needs, parents with children receiving special education services have the opportunity to work with case managers and other school support to create and

implement Individualized Transition Programs (ITPs) and Individualized Education Plans (IEPs). An IEP/ITP is a federally mandated document and process focused on the special needs of a student with disabilities. Creating this document involves collaboration between a team of educators, psychologists, and service providers (e.g., speech and language pathologists, occupational and physical therapists, vision and hearing specialists, nurses, etc.). Local Regional Centers are agencies providing overall assistance to people with disabilities outside of the school setting, including coordination of plans and services. Professionals from the Regional Center are assigned to a student, and they are often involved in the IEP/ITP school processes to provide interagency collaboration and input for the benefit of the student. Family members, teachers, educational rights holders, and sometimes advocates, attorneys, or privately-hired professionals can also be involved. All members meet to design and create an annual (or as often as needed) educational plan for the student. As teams meet, there is often a large variety of ideas, many interpretations of plans, and many voices from the team which substantiate a need for positive interactions among team members to streamline the process of IEP/ITP creation (Spann et al., 2003).

IEP/ITPs and positive team dynamics assist in times of change such as life course transitions following the senior year high school experience. One critical life course transition as a special education student is moving from secondary school services to public adult services. While many transitions will occur in the school life of a child with special needs, to eliminate or decrease the stress of these transitions, school staff attending IEP meetings need to create a supportive environment. At the core of a supportive environment is a clear, seamless life-course transition plan built on a foundation of trust among members of the IEP team. This trust is

cultivated through collaborative and meaningful IEP team meetings by modeled supportive behaviors of the team members (Spann et al., 2003).

Statement of the Problem

Times of transition for students with special needs from high school to post-school life are not comparable to those of their typically-developing peers (Janus, 2009). Social and daily living (dis)abilities impact a student's abilities to transition into adulthood and learn or utilize the skill sets needed to navigate the world as an adult and productive member of society. The time of transition from high school to adulthood is a time when an even greater number of students "fall through the cracks"; and, more specifically, those who are of a minority population and severely impacted by disabilities (Annamma, 2016).

While all parents feel some pressures in IEP meetings (Esquivel, Ryan, & Bonner, 2008), parents with children who have moderate to severe disabilities bear even greater stress placed upon them during the life-course transition from high school to the next phase of learning and life. Parents are not the only ones under stress, as other members of the IEP team also have high levels of stress to ensure they do what is best for the student with proper supports in place (Martin et al., 2006). Within the IEP team (including before, during, and after IEP meetings) it is the responsibility of each team member to provide informative and productive input surrounding present levels of performance, services needed for the student, goals, accommodations, modifications, and transition plans, or Individualized Transition Plans (ITP). These IEPs do not need to be stressful when positive behaviors occur from all team members, elicited by a facilitator. Creating a trustful and supportive team dynamic ensures a collaboratively seamless transition for the student, easing the negative emotions of families (Beck & Desutter, 2019).

However, often, teams, including families, find themselves navigating uncharted territory in how best to meet the highly specialized needs of their student/child as they enter adulthood.

These transition IEP meetings work best and lower stress for all involved when using best practices based on research. Best practice, as it is now, is often seen as entailing standardized, formal assessment of the student prior to IEP/ITP meetings. However, rigid regimes, such as standardized assessments and protocols, have the potential to leave families feeling unsupported, unheard, and frustrated during life-course transitions (Lord Nelson et al., 2004). ITP planning procedures call for extensive involvement of all stakeholders, which can be difficult for IEP team member service providers, who can feel overworked with heavy caseloads and underprepared to facilitate a positive IEP team dynamic (Brunsting et al., 2014). Additionally, IEP teams do not always know which behaviors are viewed by families as emotionally supportive during planning and life-course transitions for students.

Purpose of the Study and Research Questions

This study examined the experiences of family members during a life-course transition for their children with disabilities, specifically with respect to the IEP/ITP transition meeting. Life-course transitions are profoundly impactful on the families' lives as they navigate their children with moderate to severe disabilities toward adulthood (Brotherson et al., 1993). Garnering an introspective viewpoint from the parents on how IEP team members are creating (or not creating) a positive IEP team dynamic provided needed insights into how to provide positive outcomes through the facilitation of intentionally-supportive IEP meetings. As a secondary special education teacher and case manager currently practicing in the public education system, I unveiled the experiences and perceptions of IEP/ITP meetings from the

perspective of the educational rights holders and family members. This study will address the following research questions:

1. How do parents of students with moderate to severe disabilities experience the transition of their child to post-secondary life when supported (or not supported) by public school IEP/ITP team members?
 - a. How are Quality of Life (QoL) domains and indicators being met (or not met) for students and families experiencing the transition to adulthood?
2. How do parents of students with moderate to severe disabilities perceive IEP teams prior to and during their child's exit from secondary schooling in the transition to adulthood?

This qualitative study used a phenomenological approach to illuminate family members' perspectives as they went through the transition to adulthood for their children with disabilities.

This approach allowed the researcher to gain an understanding of how different people experience a similar phenomenon (Creswell & Poth, 2016). The study employed interviews to document, describe, and analyze pivotal moments within IEP meetings and through transitions, as explained through the voice of the parents and family, to determine how IEP team member behaviors and actions have had an impact on the transition experience for the family.

Information from this study has the potential to inform the field and IEP team members about the impacts and importance of positive team dynamics and to further inform empathy-based practices in the public school systems.

Theoretical Frameworks

Intersections of Schlossberg's Transition Theory (Schlossberg, 1981) and Schalock's Quality of Life Domains (Schalock et al., 2002) were used in conjunction with each other as a platform from which to understand the IEP/ITP transition experience for parents of students with

disabilities. This provided a complex, yet comprehensive, approach to researching and intersecting data, from which strategies for increasing supportive and meaningful IEP/ITP meetings can be developed to better inform IEP team member practices.

Schlossberg's (1981) transition theory model for human adaptation in transition was applied in education shortly after its introduction in 1981. The framework and research linked to the transition theory include identification of the life-changing event, perception of the transition event, environmental characteristics through the transition, characteristics of the individual impacted by transition, and adaptation as seen through moving and balancing resources, deficits, and perceptions of surrounding environments.

The Quality of Life (QoL) framework, domains, and indicators provide IEP teams and researchers with areas to explore and address as a student transitions into adulthood (Krishnasamy et al., 2016; Schalock et al., 2016). The use of this framework encompasses a more student-centered and comprehensive approach to creating transition plans. Eight domains are used to describe areas that impact a person's quality of life through the framework, including physical well-being, material well-being, emotional well-being, personal development, rights, social inclusion, interpersonal relations, and self-determination. Goals for unfolding a plan through the QOL framework include increasing self-determination in students, advancing the scope and development of instructional programs, amplifying inclusion in schools and communities, and building on and enhancing the various community resources available for students and families (Halpern, 1993). Psychological well-being, personal life satisfaction, quality of the environment, measures of growth and mastery, health, and economic stability are topics addressed through the QoL framework (Halpern, 1993).

In sum, using components of Schlossberg's Transition Theory, coupled with components from the Schalock's Quality of Life Framework (QoL), parents' perceptions of support from other IEP team members during Individualized Transition Plan meetings are explored to better serve students with moderate to severe disabilities through research-based strategies. These theories and frameworks will be discussed in more detail in Chapter 2.

Significance

This study sought to understand how parents experienced the processes of IEP/ITP teams during their child's transition to adulthood in relation to their family's quality of life. Research on the transition of students with moderate to severe disabilities to adulthood, and the IEP/ITP meeting experience, shows that parents and families often feel unheard while feeling overwhelmed with the dearth or overabundance of information and support (McDonnell & Hardman, 2009). Laws regarding special education transitions and plans set in place by the federal government create a skeleton of support for students with moderate to severe disabilities (Rehfeldt et al., 2012). IEP/ITP teams desiring a seamless transition for students must collaborate and determine how best to use IEPs and ITPs to guide the implementation of greater supports for students and families. This study is significant because current research surrounding familial experiences in IEP meetings shows that families do not always feel supported by school team members (Nowell & Salem, 2007). This study sheds light on the experiences of families with IEP/ITP teams as they collaborate with other team members to transition their child to adulthood. Negotiating the process of transition to adulthood for families comes with external, as well as systemic, stressors often overlooked by team members working with the families. Understanding current IEP/ITP practices, perceived as supportive or unsupportive by family members, could counter current protocols and team member behaviors to bolster federal

mandates and inform district employees for greater amounts of supports increasing family quality of life through the time of transition to adulthood.

Organization of the Dissertation

Chapter 1 provides a broad overview of the study including law and literature in special education and transition, statement of the problem, purpose of the study, theoretical frameworks, significance of the study, and definition of terms. Chapter 2 is a review of the literature on how families with children moderately to severely impacted by disabilities perceive special education teams during transitions to adulthood. First, the IEP/ITP planning process and stakeholder roles in a supportive team are discussed for a background understanding of systems in special education. Secondly, special education frameworks and theories are explored in relation to transitions in special education. Finally, the components of building a trustful and supportive IEP/ITP team to meet the concerns of students and families are discussed in the literature review. Chapter 3 describes the design of this qualitative study, data collection and analysis, limitations of the study, and the ethical considerations needed to minimize risk to the participants of this study. In Chapter 4, I analyzed the data and discussed findings. Chapter 5 contains connections to prior research, implications of the study, suggestions for further research, and conclusions. The bibliographical references and appendices are included at the end of the study.

Chapter 2: Review of the Literature

The following review of literature examines behaviors and attitudes within IEP teams, impacting perceived emotionally supportive behaviors and interactions in IEP meetings for the families of students with moderate to severe disabilities transitioning out of high school and into adulthood. The review will address three focus areas: (1) the IEP process and stakeholder roles in a supportive IEP team, (2) special education transition theories and frameworks, and (3) building a trustful IEP team to meet the concerns of students and families. These lenses of looking at possible impacts of IEP team members and family interactions will offer a perspective of special education, including the complexities of following the law, while also providing emotional support for families.

Before delving into the literature, it is important to explain further the IEP transition process. IEP team member involvement and collaboration with the family is consistently under-defined through the transition process, as prescribed by school district protocols and Individualized Education Programs (IEPs), further straining information-filled meetings (Kalyanpur et al., 2000). School districts and federal laws encompassing domains of transition for a student with special needs do not necessarily provide a comprehensive outline describing IEP team processes. As a team convenes, there are large amounts of work to be done to create an IEP/ITP, which is required to be individualized to meet the specific needs of the student.

Creating an IEP/ITP means time and energy must be spent: on creating the plan, ensuring the plan aligns with the domains federally required by law, and the plan contains achievable objectives and goals. The volume of time and work associated with the creation of an IEP in a meeting does not allow much time for more comprehensive transition planning, such as the utilization of person-centered planning requiring outside school time to complete in a holistic

and impactful manner (Miner & Bates, 1997). Most IEP teams feel unprepared due to a dearth of guidelines and research surrounding how to best support parents and families of students with moderate to severe disabilities throughout their time in public school systems (Davies & Beamish, 2009; Woods et al., 2018). If a team is unprepared, this can elicit a stress response from team members, further compounding time constraints, as teams settle into tackling the IEP/ITP process (Beck & Desutter, 2019).

The lack of evidence-based practices related to the IEP/ITP process in public school systems needs to be addressed for parents, families, case managers, service providers, and agencies to effectively facilitate seamless life-course transitions for students with moderate to severe disabilities (Test et al., 2009). As a result of the lack of research on evidence-based practices in this field, questions regarding specific roles of stakeholders arise resulting in inconsistent interpretations from most members of an IEP team (Hartmann, 2016). Hence, when families feel “unheard” in the IEP and life-course transition process, it may lead to discord among team members and families of students with moderate to severe disabilities (Woods et al., 2018).

Discord among IEP team members interferes with a seamless transition model which requires stakeholders to invest themselves in the process of life-course transitions; however, specific guidelines for communication, assessment, and family interactions for IEP team members are vague for those working with students impacted by moderate to severe disabilities (Landmark et al., 2013). With a poorly laid foundation for life-course transitions and IEP transition meetings, there is the possibility of dissonance if parents perceive the IEP team members as unprepared to meet the individualized needs of their child. For example, there are a vast array of topics and knowledge IEP team members must be prepared to provide including

possible new physical placements for school, projections for future life, education, employment goals, and preparing the student and their family for life outside of public education.

Another area of consideration in preparing students with moderate to severe disabilities for life after high school is communication between school staff IEP team members and students' families. The doors to communication can be negatively impacted by systemic and systematic barriers, such as lack of time for comprehensive life planning, and lack of support from district office leaders and site administrators. Unclearly marked communication norms from leaders in public schools can leave the doors to communication between team members and family strained in the process of life-course transitions (Hirano et al., 2018).

Systemic (issues and implications within and woven into systems) and systematic (plans created for a majority in order to carry out a goal) barriers preventing equity in special education services include different languages and cultural backgrounds, inaccessible healthcare and other service systems, knowledge regarding assistance, opportunities for involvement in school and student planning, and culturally normative behaviors (Hirano et al., 2018). When tackling these barriers, it is important to keep in mind that the creation of IEPs and ITPs is intentionally collaborative; however, the ambiguity of norms and the obstacles to supporting families is not cohesive with the collaborative, seamless transition model. IEP teams should be given the necessary skills and strategies for how to support families during times of life-course transitions. When IEP team members are given the tools and knowledge necessary to support families through life-course transitions, the collaboration between the families and the IEP/ITP team is far more effective for positive post-school outcomes (Plotner et al., 2018).

IEP/ITP Process and Stakeholder Roles in a Supportive IEP Team

IEP/ITPs. Students identified as having special needs in accessing school curriculum and expectations will go through multiple transitions through their years in public education systems. One initial transition occurs when a child with disabilities enters school for the first time or is identified as a child with special needs in education. When this happens, an Individualized Education Plan (IEP) is created to guide the individual needs of the child in accessing educational programs and school culture. IEP meetings are held annually, or as requested by one of the team members. An IEP team is made up of a multitude of both school and family stakeholders. Because these meetings have many professional staff members using acronyms and technical language and suggesting new or different program directions for the special education student, families can be filled with fear and discomfort in the process caused by ignorance of the terminology and unfamiliarity with various programs (Tucker & Schwartz, 2013). As a portion of collaboration for positive post-school outcomes, students identified as eligible for special education in U.S. public school systems qualify to receive services and schooling through a Free and Appropriate Public Education (FAPE) from birth through 21 years of age. FAPE is guaranteed for all students in the United States public school systems, and it means students will receive an education with modifications and accommodations as needed to meet the needs of each student (Education for All Handicapped Children Act of 1978). Special education and related services are prescribed through each student's IEP, as federally mandated following the laws of The Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004, Title 34: Education, Part §300.43). This act mandates that an Individualized Transition Program (ITP) will be created and implemented by the time a child with a disability (or disabilities) is 16 years of age. A primary goal of the ITP is ensuring students engage in

activities, curriculum, and learning leading to as much independence as possible in post-secondary life. It is each human's universal right to live a productive and meaningful life (Mlynaryk et al., 2017).

Ascertaining the maximum independent achievements for students with special needs means IEP teams engage and collaborate to generate a plan aligning with federal law. According to federal law (20 U.S.C. 1402 (34)), a transition in special education is defined as a set of results-oriented tasks and transition activities geared toward improving a student's academic and functional achievement. Post-secondary education, vocational skills, integrated and supported employment, living scenarios for adulthood, and community participation are the domains' guiding goals and objectives in the creation of the ITP. Domains are met in ITPs, including instruction and related services outlining community experiences as appropriate, and the development of post-secondary goals. When intertwining ITP activity domains and aligning student activities, the student's strengths, preferences, and interests are accounted for in developing the plan; voice from all IEP team members is equitably shared in the IEP/ITP process; and, federal and state special education laws are followed throughout the process.

In following state and federal laws, the ITP contains three sections for goals and activities related to the transition from high school: education, employment, and independent living. The primary goal of the ITP is to ensure students engage in activities, curriculum, and learning leading to as much independence as possible in post-secondary life. The ITP, which is created based on students' preferences, strengths, and interests, drives the IEP goals for a student over the age of 16 in special education. IEP goals must relate to the ITP goals in some form in order to prepare students for life in the workforce and community. The transition team developed from the IEP team must: (a) identify the student's vision and goals for post-secondary life; (b) discuss

the capabilities of the student; identify age-appropriate, ability-appropriate, and measurable goals; (c) establish services that build on strengths and identify needed accommodations and modifications to general education curriculum, and (d) define each transition activity and who is responsible for the activity and time frames.

One common misconception is that planning for a life-course transition involving an ITP should solely take place in the middle school and high school program timeframes for a student. This concept has not only been disproven as best practice, but longitudinal studies have shown creating future life goals with incorporated life-skills curriculum/activities for a student at an earlier age only benefits the student (Papay et al., 2015). When considering the complexity of diverse and intricate factors pertaining to transitioning a student who has a disability requiring collaborative interagency work with numerous services, supports from outside agencies, and reaching goals set in the ITP, IEP team service providers, at all levels of education, should be integrating the ITP as much as possible in educational and functional skills learning settings.

Stakeholder Roles. Integration of ITP activities supported by vigilant IEP team members is evidence of engaged IEP team members valuing the mission of the IEP/ITP. For students with moderate to severe disabilities, parents' and teachers' expectations surrounding post-secondary outcomes are proven to be influential in life-course transitions (Shandra, 2011). Even when IEP members have high and reachable expectations for the student, persistent concerns are still felt by teachers and parents. Feelings of concern by stakeholders are understandable, as statistics show students with a disability are more likely to drop out and be unemployed (Prince et al., 2013). Parents' concerns regarding their child's future are an expected part of active participation in education; as such, parents are most often the medical and educational rights holders for a student, which means they are the sole decision-makers for their child. Parents and IEP team

members must work through concerns brought to IEP/ITP meetings, as well as tackle challenges arising and impeding the path to building and bringing together a cohesive transition IEP team.

When considering the team, possible impediments to collaboration, and extensive work in preparing an effective ITP, it is necessary to ensure all stakeholders have and hold a valued voice in the process. Voices of many team members including the student, family members, related service providers (speech, occupational, and/or physical therapists; deaf and hard of hearing specialist, visual impairment specialist, and others as needed), administration, case managers, outside agencies as appropriate (i.e., Regional Center worker), general education teachers, school psychologists as needed, and any other members of the family, all have to be heard in a limited amount of time during an IEP/ITP meeting. At times, a family may choose to hire an advocate and/or attorney to assist them with navigating the legalities and nuances of the IEP/ITP for the aim of ensuring IEP teams are meeting a child's needs. With this element of a new IEP team member, the feelings of IEP team members lean toward distrust. Whether the ingredient of an advocate or attorney is adding to the IEP team's trust or distrust, the dynamics existing within an IEP team can be complex and non-linear in theory and practice (Hamdani et al., 2011). Voices from all should be heard through the complexity of the team, with student voice primarily guiding team decisions.

Student Involvement in the IEP/ITP Process. IEP/ITPs followed with fidelity have been shown to positively impact student outcomes (Test et al., 2009). Many students with moderate to severe disabilities can face challenges with self-determination and involvement in the IEP/ITP process; but, with the proper planning, supports from stakeholders, and activity creation through the use of modifications and accommodations, even students with the most severe disabilities should have a voice in the IEP/ITP creation and implementation at school

(Lindsay et al., 2018; Hamdani et al., 2011; Giangreco et al., 1993). Meeting these needs for a student with moderate to severe disabilities increases access to IEP meeting input. Voice from individuals with disabilities regarding post-secondary education should come first, providing students with practice in self-determination skills through the IEP/ITP process. Ideas and skills practiced in self-determination change over a person's lifetime, so students are given every opportunity to express their current wants and needs during IEP meetings (Ankeny & Lehmann, 2011).

Special Education Transition Frameworks and Theories

Individual Transition Plans (ITPs), developed in conjunction with a student's IEP, have been a portion of the IEP process for students with special needs since they were introduced under the Individuals with Disabilities Education Act in 1990 (IDEA 1990, Title 34: Education, Part §300.43). Federal law requires every student in the United States public school systems to be afforded the right to a Free and Appropriate Public Education (FAPE), including all students of all ability levels. As a result of the addition of ITPs into the IEP, and in accordance with FAPE, teams come together to create the most relevant goals, objectives, and activities to bolster a bright and productive future for students with special needs. Since the introduction of ITPs thirty years ago, growing numbers of frameworks and theories are continually introduced to guide current practices in special education transition. Rooted in "quality of life" outcomes with the long-term successful integration of people with disabilities in society is best practice (Halpern, 1993); however, transition research of the past has rooted itself in federal laws regarding special education (Rehfeldt et al., 2012).

Transition Theory and Quality of Life Frameworks. Frameworks pertaining to transition for the students themselves and quality of life outcomes have been formulated since

the 1990s to inform IEP/ITP team members and their decision-making for students with moderate to severe disabilities. These frameworks have provided a foundation to continue special education research (Lindsay et al., 2018). In addition to topic-specific frameworks, other models have been applied in the area of transitions in education.

Schlossberg's (1981) transition theory model was originally created for adults going through transitions throughout life; it has since been applied to research in the field of education. The theory hones in on an individual's transition experience through a specific event and time period. There are four factors of Schlossberg's theory that define how a person moves through a transition – Situation, Self, Support, and Strategies. These factors are determinants of the transition experience perception for the individual (or family). Linked to the framework and research, the phases of transition are delineated based on an individual's movement through the transition event. The framework (Table 1) and research linked to the transition theory include identification of the life-changing event, perception of the transition event, environmental characteristics through the transition, characteristics of the individual impacted by transition, and adaptation as seen through moving and balancing resources, deficits, and perceptions of surrounding environments. Contrary to current, normative practices in special education, using this theory in transitions does not allow much leeway for the extremely specialized accommodations and modifications to be easily woven into a plan; rather, it informs the IEP team members of areas in the students' lives to consider as students transition from high school post-secondary life.

The Quality of Life (QoL) framework provides IEP teams and researchers with areas to explore and address as a student transitions into adulthood (Krishnasamy et al., 2016). It has been found that “taking stock” of QoL domains and indicators throughout the processes of life-

course transitions for any person is an important part of creating positive life changes (Verdugo et al., 2005; Anderson et al., 2011). The QOL framework domains encompass a more student-centered approach to creating transition plans than Schlossberg's Transition Theory, which describes the movement through the transition. Goals for unfolding a plan through the QOL framework include increasing self-determination in students, advancing the scope and development of instructional programs, amplifying inclusion in schools and communities, and building on and enhancing the various community resources available for students and families (Halpern, 1993). Subjective and objective components in both high and low qualities are presented interconnectedly in a visual organizer. Psychological well-being, personal life satisfaction, quality of environment, measures of growth and mastery, health, and economic stability are topics addressed through the QOL framework (Halpern, 1993). Models such as Schlossberg's transition theory and Schalock's quality of life framework can be used in conjunction with each other to build in-depth transition plans tending to the many needs of students with moderate to severe disabilities. At the core of this planning will be the creation of a trustful and supportive IEP/ITP team and environment, placing student and family voices first, which will provide ease in collaboration and communication between the team.

Building a Trustful and Supportive IEP/ITP for Seamless Life-course Transitions

Stress impacts human thought processes and decision-making; parents going through grief-driven emotional stress when their child has a moderate to severe disability are likely to feel disconnected from those around them (Woodman, 2014). Stress from the everyday life of being a caretaker for someone with specialized needs causes feelings of underachievement, guilt, and insufficiency translating into possible negative impacts within IEP teams (Thorin & Irvin, 1992). When voice from students and families situates first in IEP/ITP team interactions,

families are more likely to experience alleviation of stress enabling positive IEP/ITP processes. Positive and informative interactions within IEP teams elevate parents' sense of trust and willingness to participate meaningfully in dialogue throughout their child's transition to adulthood (Francis et al., 2016). IEP teams can better understand families' lives through a lens of empathy and the use of supportive interactions with families. Understanding the extreme range of emotions and difficult life circumstances that riddle the lives of families with children who have disabilities will prepare IEP team members to use empathic lenses and approaches for building positive rapport with students and families.

Recurrent Grief in Parents of Transition-age Students with Moderate to Severe Disabilities. Family voice is at the center of determining the needs for a student with moderate to severe disabilities. In consideration of family voice in IEP/ITP teams, teams should be aware that caring for a child with moderate to severe disabilities carries great amounts of stress, emotional variances through time, and logistical life-planning for the entire family (Krishnasamy et al., 2016; Jones & Gallus, 2016). Once a child reaches the age of majority, critical life changes occur not only for the child-student but also for the family members and caretakers (Brotherson et al., 1993). Life changes create greater amounts of stress-based emotions possibly impacting the decision-making process for parents. Even greater stress is placed on students and families as students near the age of transition out of high school and into adulthood. Stress due to transition is brought on by many factors (Leonard et al., 2016). This stress can lead to recurring feelings of grief at different points in time, impacting families, and the decisions related to IEPs/ITPs (Brotherson et al., 1993).

A parent of a child with a disability will go through many stages of recurring grief throughout her lifetime. A constructionist approach to grounded theory is employed in Brown's

(2016) study to glean a deeper perspective into the recurring grief imminent throughout life for mothers of children with intellectual disabilities. Revealing information regarding specific points in time illuminates when mothers are most impacted by grief, Brown (2016) argued there are eight grieving points in time during which the theory of recurring grief occurs in these mothers. Initial diagnosis is one of the most stressful times in the life of the families who are given the news their child has a disability. Double mourning is seen shortly after this time, which causes the mothers to grieve not only the diagnosis but the reality of the life ahead for them. Public reaction to a mother's child with a disability, as well as exclusion or inclusion of the child, triggers a grieving period within the parent. Milestones throughout the child's life (those lost or found) and fears of the future are also points when the mother will experience grief. These points of grief, and meaning-making in identity and agency as an individual for the child with disabilities, cause strain on the mother and the entire family. Insights into familial experiences provide a lens for IEP team members to better empathize and understand the need for emotional supports for families as they delve into life-course transitions for their children with disabilities (Brown, 2016).

Stress impacts human thought processes and decision-making, and parents go through grief-driven emotional stress when their child has a moderate to severe disability (Hassall et al., 2005). Stress from the everyday life of being a caretaker for someone with specialized needs causes feelings of underachievement, guilt, and insufficiency translating into possible impact on an IEP team. When parents feel "unheard" in IEP meetings, advocates and attorneys provide a sense of security for them through the IEP/ITP processes (Nowell & Salem, 2007).

Systemic and systematic barriers to family involvement. Students with the intersectionality of minority race, spoken language, and disability(ies) face more barriers to

accessing education in the public school systems than their general education counterparts (Annamma, 2016). Systemic barriers are those placing constituents in a place of inability to work within the systems of special education. Examples of systemic barriers in public special education are language barriers, physical barriers, lack of system knowledge, or misalignment of culturally normative behaviors (Abriza & Ahmad, 2017; Jung, 2011). These barriers have the potential to create a lack of access to FAPE (Free and Appropriate Public Education) for students of color (or other minority identifications). Families of students are negatively impacted by special education systems which are meant to be navigated by the majority population (Hirano et al., 2018).

Majority populations flourish in the systems of special education currently in place in public school systems (Annama, 2016). Systemic potential for these students is easily accessible for white general education students compared to their special education counterparts. School attitudes and beliefs about family involvement lean more positively toward white, middle-class families (Hirano, 2018). Families can be inadvertently labeled as uninvolved if they are unable to be involved in such a form as volunteering in the classroom. Families labeled as “uninvolved” potentially miss out on the social capital by ensuring supportive IEP/ITP members (Hirano et al., 2018; Annamma, 2016). This social capital includes personnel who are readily accessible and willing to provide pertinent information to the families.

An absence of accessible information surrounding making the best decisions for a child with special needs leaves families hurdling complex special education systems. Without accurate information, families are disabled in providing proper advocacy and support for the highly specialized needs required for their child’s education and transition into adulthood (Hirano, 2018). Unclear or misaligned expectations coupled with a lack of resources for the

families in regards to the life outcomes for students negatively impact the seamless transition to adulthood (Riesen et al., 2014).

A Need for Familial Supportive IEP Teams. In considering parental stress surrounding transition, and essential components of positive IEP team cultures, trust is one of the most important among all IEP/ITP members, as differences of opinion can arise between parents, administration, service providers, and case managers (Lake & Billingsley, 2000). Conflicts occur regarding resource use, placement, goals, services, and best practices revolving around the optimum learning for a student with disabilities (Lake & Billingsley, 2000). During times of IEP team conflict or discord, IEP team members should always consider family voices forefront (Defur et al., 2001); when creating an IEP/ITP, parent input most often prevails, as they are rights holders and caretakers for the students when they are not at school (Francis et al., 2015). Parents and caretakers should be “heard” through a trustful and supportive IEP team dynamic. Familially supportive IEP teams glean more productive collaboration and education efforts for students with moderate to severe disabilities (Test et al., 2009).

A trustful and supportive IEP team can assist families and students through the IEP/ITP process allowing the students and families to feel more comfortable with the IEP meetings and processes. The entire IEP team, including the student, often feels overwhelmed with the oft-times bureaucratic and information-filled process of creating and implementing the IEP/ITP, both during and after meetings (Test et al., 2009). This overwhelming feeling often begins during the process of creating an IEP upon the initial diagnosis of a student with disabilities. During this initial IEP meeting, the Individualized Education Program (IEP) created for a student in special education, outlines the goals and services to implement in the school environment for one year. After the initial IEP creation and meeting, IEP teams convene once a year (or as needed

when a member calls for a meeting), to review and create a new and appropriate IEP. With stress-related emotions and uncertainty of the future for their child, there is a need for perceived supportive behaviors from IEP team members by the family.

Stress for parents increases through the transitions their child faces during the school-aged years and beyond (Krishnasamy et al., 2016). One transition difficult for both parents and children is the transition from high school to post-secondary life (Thorin & Irvin, 1992). This period of transition begins at the beginning of high school, or before a student turns 16 (as mandated by federal law), at which time the IEP team meets to create an Individualized Transition Plan (ITP) for the student. The IEP/ITP team must give input and sign in agreement to the IEP/ITP for a student with disabilities or in need of special education services, with the voice of the student taking priority. The voice and wishes of the student should inform the program and services necessary for a comprehensive education plan (Cavendish & Connor, 2018). Teams make decisions based on what is best for students; and, if the ITP requires specific services to reach a goal, then the district must provide those services and providers. IEP/ITP services and providers prescribed in the plan must be implemented by the team, and data collected on the goals should be collected and analyzed for quarterly progress reports to the family and team. Within the IEP, the ITP drives the annual goals outlined and set for the upcoming year for a student with moderate to severe disabilities. IEP team members are responsible for creating activities, which are derived from the ITP, and collecting data on outcomes of the activities to inform the next year's IEP/ITP. Goals, activities, and data should build upon each other through the school years to develop the skills necessary for post-secondary life.

Creating the IEP/ITP is the goal of IEP team members; and, one of the core missions of IEP team members is fostering and building positive relationships within the team. Collaboration involves providing critical and pertinent information to other team members informing the IEP/ITP and other programs meeting the needs of a student with moderate to severe disabilities (Fish, 2008). Expectations from parents and families, and facilitating the creation of symbiotic connections within an IEP team amongst family members, administration, service providers, and other support staff can be a difficult undertaking for many people (Ryndak et al., 1996). Intricacies and nuances of fostering a supportive and trustful IEP team are a great responsibility and necessitate excellent interpersonal skills.

Skill sets involving the facilitation of supportive IEP teams and meetings are ascertained through the facilitation of meetings, positive communicative input, and meeting and member facilitation and experience. Facilitators of meetings must negotiate many professional roles and identities while maintaining professional conversations regarding the success of the student. Contexts surrounding the IEP meeting environment guide facilitation of the process while supporting families through the IEP/ITP process (Beck & DeSutter, 2019). Utilizing the context of the meeting, IEP team members should be positioned in such a manner that allows them to provide the utmost informative input for the IEP/ITP. Content-specific knowledge does not necessarily place an IEP team member in a position to provide the most beneficial input into the programs or plans. It is the role of the facilitator to engage teams in creating IEP/ITPs in collaboration with others. Team members who have strong and effective communication skill sets are more impactful in creating plans leading to positive outcomes for students with special needs (Beck & DeSutter, 2019). Providing a supportive environment for an IEP meeting requires team members to put in time and energy through perceived positive behaviors and

interactions with families. Symbiotic relationships within the IEP team result in a perceived emotionally supportive environment for the family and team members.

Stakeholder Dynamics: Trust and Support for Families. It is known that student and family involvement is best practice when creating IEPs/ITPs for a student with disabilities (Hirano et al., 2016). Long-term success in life for these students hinges on productive and effective planning from all stakeholders (Woods et al., 2018). Parent and student involvement, along with input from all stakeholders in the ITP creation, is considered a priority when it comes to effective outcomes for goal attainment (Cavendish & Connor, 2018). Students with moderate to severe disabilities face immense challenges in reaching post-secondary goals in life, and these goals often range in complexity and attainability (O'Brien, 2006). Trust and perceived positive emotional support for families going through this life-course transition provide the opportunity for an IEP/ITP team to collaborate in an effective and impactful manner (Tucker & Schwartz, 2013).

As students transition services from public school systems to other federally- and state-funded assistance agencies (and preferably before this stage), the concept of distributed leadership in the form of service integration across multiple systems works best for meaningful work and life outcomes (Certo et al., 2008). The IEP and ITP stakeholders, and more specifically, non-family members, should be aware of families having different styles of advocacy, means of support, and expectations regarding support from the team (Rehm et al., 2013).

IEP Team Member Perceived Supportive Attitudes and Actions. As stakeholders convene annually, or more often as needed, to create the IEP/ITP, team members must stage a tone and setting aligning with positive interpersonal dynamics (Martin et al., 2006). Through

this positive tone and setting, members and facilitators must engage the team in making decisions regarding a student's education and transition plan. Transition and creation of transition plans have been proven to be the areas in which stakeholders and families feel the least confident in making decisions for a student's future (Martin et al., 2006).

Body language, appearance, tone of voice, and other actions and attitudes surrounding perceived emotional support for families are taken into account by IEP team members when collaborating with others for the support of transition-age youth and family members. Attitudes and actions can be and are perceived and interpreted by others through varied lenses, such as the lens of a grieving mother. Interpretation of behavior and information through grief-stricken lenses can skew a relationship within the IEP team, causing rifts or strife in the team dynamic (Smith et al., 2001).

In contrast to possible emotionally-driven thoughts, speech, or action, voice of individuals with disabilities regarding post-secondary education should come first, as the idea and skill of self-determination changes over a person's lifetime (Ankeny & Lehmann, 2011). Rooting the IEP/ITP process in the voice and advancement of students first has proven to be one strategy for eliciting a sense of comfort for students and families going through times of transition in education. Providing agency for students with moderate to severe disabilities through their years in special education creates within them a driving force for self-determination (Field & Hoffman, 2012). With student voice coming first, the parents' voices are considered to be the second strongest voice in making decisions regarding the education and services for their child with disabilities (Cawthon et al., 2018). Bringing together an IEP team where all voices feel "heard" yields feelings of positivity surrounding the relationships and trustworthiness within

each other; and, in turn, seamless transitions into adulthood are more likely for students with moderate to severe disabilities.

Summary

Parents of children with moderate to severe disabilities face challenges that parents of neurotypical children do not face in public education systems. These systems were built for a majority population receiving minimal accommodations and modifications in general education courses. Parents who have children in special education collaborate with agencies and school personnel far more than parents of children in general education. They are greatly impacted by stressors surrounding the complexities of these interactions and systems. As children with special needs go through various transitions in school and agency programs, parents endure even more stress in coordinating, planning for, and implementing these transitions. IEP teams meet annually at a minimum to create IEPs (and ITPs once a child enters high school or before the age of 16) which lay out the goals, activities, and supports for student success in and through the public school systems. These meetings, as well as transitional periods for students, can elicit stress-induced feelings in parents which could negatively impact perceptions of support and interpersonal dynamics within an IEP team. The use of a transition framework and a lens of empathy from team members eases the stress of IEP/ITP development and processes involved with special education and transition processes. Collaboration (with student and family voice at the forefront) including positive interactions and behaviors between team members yields a more successful transition from public school systems into post-secondary life for students with disabilities.

This review of literature presented three overarching themes: (1) the IEP process and stakeholder roles in a supportive IEP team, (2) building a trustful IEP team to meet the concerns

of students and family, and (3) special education transition theories. Perceptions of support are not commonly described when families of students with moderate to severe disabilities are in IEP/ITP meetings. Reliance on collaboration for seamless transitions in special education is necessary, but not often felt by parents and families. Theories of transition suggest that proper strategies and supports in place create an easier transition in life changes such as the transition to adulthood.

The reality, for parents of children with moderate to severe disabilities who are going through the transition to post-secondary life, is that many government-paid, family assistance services end when students hit two milestone ages, 18 and 22. Research shows that these families often feel uninformed or unheard in IEP/ITP meetings, as well as in regards to services for their children (McDonnell & Hardman, 2009). In order to change the perceptions of support and current transition practices to those which are positive and meaningful, it is important to better understand which behaviors, actions, or attitudes parents and families experience in these meetings. Schalock's quality of life domains and Schlossberg's transition theory will assist with placing perceptions of familial support by IEP team members into specific points in time, while also providing the lens for family members' quality of life throughout the transition process. Experiential knowledge of life-course transitions and IEP/ITP meetings as portrayed by the words of the family members will be powerful narratives to add to the growing field of special education transition research. Having the voices of students and families heard should continually be of priority to those working in special education. There is little research surrounding better practices of IEP team members, their behavior during meetings, and how practices of certain behaviors or attitudes impact the families. This research aims to place student and family voices at the forefront of education research in the area of transition to

adulthood for students with disabilities. Their stories have not been prevalent enough in special education research and studies.

Chapter 3: Methodology

Review of Study Purpose

The previous chapter outlined the multi-dimensional approach for planning required by IEP team members to create and implement transition plans for students with moderate to severe disabilities. Complexities involving IEP member attitudes, understandings, and behaviors being perceived as supportive (or unsupportive) during the time of transition for the student and family members are addressed through the assimilation and merging of two pertinent frameworks used during the data analysis process. The framework combines two theories/frameworks, from which special education research has leaned in the area of life-course transitions for students with disabilities. In using this framework as a reference for familial experiential narrative development, I was able to create a descriptive portrayal of the transition experiences and quality of life for families to inform IEP/ITP team practices.

The two overarching questions which guided this study include:

1. How do parents of students with moderate to severe disabilities experience the transition of their child to post-secondary life when supported (or not supported) by public school IEP/ITP team members?
 - a. How are QOL domains and indicators being met (or not met) for students and families experiencing the transition to adulthood?
2. How do parents of students with moderate to severe disabilities perceive IEP teams prior to and during their child's exit from secondary schooling in the transition to adulthood?

Research Design

Qualitative research design is used to shed light on social and cultural phenomena within a given context through exploration to provide detailed information about human dynamics (Creswell & Poth, 2016). Phenomenology as an approach to qualitative research reaches into the area of understanding how different people live through similar experiences of a phenomenon (Creswell & Poth, 2016). It is also used to increase understanding of surrounding phenomena in which there is little relevant research. I chose phenomenology from which to frame and guide this study, as family member narratives revealed a variety of isolated, intricate, and detailed experiences described in the context of the same experience of transition to adulthood for their children. For example, there is research surrounding seamless transitions and IEP/ITP teams; however, there is minimal research delving into the experiences and quality of life for families experiencing their children's transitions to adulthood as they navigate stress-filled meetings and processes. The reconstructive nature of qualitative research lends itself toward deeper learning in a given field via the participants' experiences, which is the topic of research (Maxwell, 2013). Parents of students with moderate to severe disabilities have felt unheard (Young et al., 2016) during these transition meetings for their children. Few studies have addressed the quality of life for parents and families as they experience stages of transition in their interactions with public school IEP team members (Boehm et al., 2015).

This study provides a detailed portrayal of these families' experiences through their child's transition to adulthood. This study delves into phenomena within transition theory stages for families with a child who has a moderate to severe disability, as seen through IEP meeting dynamic perceptions and understandings by family members. It was designed to garner parent voices, placing this minority population into an empathetic lens for IEP team members

navigating the life-course transition process for students with moderate to severe disabilities. To capture the transition experience of families through the perceived dynamics in IEP/ITP meetings, data was collected from the use of semi-structured interviews. Using an empathetic lens as an informant for data collection and analysis, as well as the framework I constructed for analyzing the data, themes regarding the perceptions of IEP teams and members of these families emerged for a powerful narrative.

Participants

For this qualitative study, families of children with moderate to severe disabilities who recently transitioned their child from a public high school into a post-secondary program (private or public sector) were interviewed to garner a holistic picture and powerful narrative regarding perceived support from the IEP team members through the transition process. Participants were selected using purposeful selection, ensuring that possible participants meet specific criteria bolstering the validity of the study. I sought out parents whose children have gone through the stages of transition to adulthood in the context of an ITP meeting within the past three years, providing an opportunity for historical narrative as a means for exploring perceptions that have possibly been changed after their student has been out of high school for longer than a year. To obtain participants who meet the requirements of this study, I used my professional and personal networks within San Diego County and local school districts. Using personal and professional contacts provided a comfort level for participants, with an assurance that we are in the special education community together for the betterment of those with disabilities. Trust between families of people with disabilities and social service entities has a history of being easily broken (Spann et al., 2003). Knowledge of intention and shared interest for the success in life for those

with disabilities provided grounding for building relationships as a researcher with these families.

Nine families who met the study criteria engaged in this research on family experiences during IEP and ITP meetings through their child's transition to adulthood. The lives of families who have a member with moderate to severe disabilities are busy with care-taking duties and collaboration efforts with agencies and other support providers. It was important to be aware of these time constraints, as well as consistent monitoring of how families were feeling throughout the research timeframe. I created conversations and participated in dialogue to build trust with the families being researched which provided comfort throughout the research process enabling them to be open and honest during interviews. Once a relationship and trust were created, the one-on-one interviews were textural and rich in information.

Recruitment

Recruitment for participants for this study came from a number of my personal and professional networks within the community of special education in North San Diego County. I feel this was the best course of action because many families of students with moderate to severe disabilities have experienced broken trust within the school systems. The systems within public education can be confusing, overwhelming, and full of barriers for these families. People with disabilities have been excluded from society and schools for the majority of humankind's existence. It is only within approximately the past 65 years that advancements and progression have occurred in the United States surrounding access, integration, and inclusion of people with disabilities into society (Rotatori et al., 2011); as such, practices within special education are premature in comparison to general education counterparts. This lack of maturation within societal systems and views, in relevance to the times, has resulted in inefficient and underfunded

systems needing review, revision, and reflection to better serve not only people with disabilities but also their families.

In order to build trust among potential participants, I reached out to trusted community members who were able to connect me to families of students with moderate to severe disabilities. Then, from an empathetic lens, I explained my study to these families and emphasized the need for further research in this area of special education. I connected with these families based on my own practitioner experiences, life experiences, and as an advocate and activist for people with disabilities.

I also sought help from the administration within the school district and supporting area agencies. First, as a current education specialist in the district, the administration had already pledged support for this research and connected me with families who have been through the transition to adulthood with their children who have moderate to severe disabilities. Secondly, I was able to connect with administration and friends who work at a local agency that provides support to students and families. This government-funded agency assists in more than 12 area districts in San Diego County. They provide services and support to school districts, families, and students throughout San Diego. The range of services includes professional development, training, workshops for families, consulting, advocacy, and specialized support services (ie, deaf and hard of hearing, vision impairment, speech, and other therapists). To reach possible participants outside of the school district, I sent an email to my colleagues at local agencies and asked that they forward it or share it with parents they know who met the criteria of my study.

Fifteen potential participants were contacted through an initial meeting via email, phone, or video conference. Of the fifteen potential participants, nine followed through with a second

contact involving an in-depth interview. The nine participants were chosen based on if they met the criterion for the study, as well as their availability and willingness to participate in the study.

Data Collection

This study was conducted during the COVID-19 pandemic which required alternative methods of data collection to be employed in order to make interviews accessible for all participants. First, I utilized phone calls and emails to contact participants to determine if participants were willing and able to participate and if they met the criteria to be involved in the study (Appendix A). Initial phone calls and emails allowed for introductions and assisted in opening the dialogue for the one-to-one interviews. Conversations with the participants gave us a chance to become acquainted and provided a space to build rapport to garner candid narratives of participants' transition experiences. Next, I conducted semi-structured, in-depth interviews with family members (Appendix B). Mandates surrounding the COVID-19 pandemic placed restrictions on how interviews were conducted; individual interviews required the use of video meetings and/or phone calls to collect data. All participants were interviewed independently. The goal of the semi-structured interviews was to allow parents to express their opinions and feelings in their own words. This is important in my research because I feel that the parents' voices are rarely present in research. I wanted to create a space for parents to express their frustrations, as well as successes, for their children in special education. These two forms of interviewing were used alongside peer debriefing to ensure the validity of data and proper representation of the authentic family experience.

This research project's success was dependent on my ability to connect and build trust with the families of students with moderate to severe disabilities. Initial informal meetings with parents allowed them to express their opinions and ideas while simultaneously providing me

time to discern if the family is comfortable moving forward with the research. Open-ended questions allowed the research process to commence from the vantage point of the family members who have experienced their child's transition to adulthood. It also assisted in creating poignant, in-depth interview questions for the process of member-checking. I used these meetings to explain the study and solicit parents' consent for study participation. The initial meetings occurred via a virtual meeting call, a phone call, or through email dialogue. Due to COVID-19 restrictions, many families felt more at ease with not meeting in person, which means that interviews could have been slightly impacted by the virtual formats. Open-ended questions for initial meetings were created to address the probable inclusion of various data collecting formats. The researcher also conducted a mock interview with one colleague to determine the interviews would each require approximately an hour to complete. These questions are included in Appendix B.

Semi-structured, one-to-one interviews followed the completion of initial meetings with families who consented to be part of the research. Options for meeting via in-person were not available as the world continued to navigate the pandemic of COVID-19. All interviews were completed via telephone and/or video conference call. These 45-120 minute interviews were used to dive deeply into the details and nuances of the transition experience for the families of students with moderate to severe disabilities. One-to-one interviews allowed family members agency in providing authentic and comprehensive narratives for the study. Having built rapport via initial interviews with participants, I found that participants were more willing to divulge details about IEP teams and team members' behaviors which could assist in sculpting supportive transition practices for the future of the field. To tend to possible interview environment variabilities, interview questions created for the one-to-one interviews were forged from an

organic and flexible perspective on the part of the researcher. The interview questions in Appendix B helped guide the interviews with families, but they were also left intentionally open for the benefit of the participants, researcher, and possible impact on results from the collected data. Within the appendix of the interview protocol, notations were provided next to each interview question to indicate which research question they each informed.

Data Analysis

All interviews were taped and transcribed verbatim using web-based transcription services, Rev.com. Interview transcripts were then coded to determine pertinent themes and categories of the transition experience. Analyzing qualitative data requires researchers to grapple with words, categories, and understandings of the social world of humanity (Maxwell, 2013). To better frame the words of the interviewees from which I collect my data, I have combined Schlossberg's transition theory and quality of life domains based on the research of Schalock (Schalock et al., 2002). Interrelated characteristics of each framework were considered for the purpose of creating the Comprehensive Transition Theory Framework for Special Education. The transition framework I created enables the researcher (or IEP team member) to better understand the process of building IEP/ITPs and components of life transitions, while also keeping the quality of life for the student at the forefront through each phase of transition.

Data from interviews were analyzed by using the comprehensive transition framework to (1) Correlate the position in a time of the transition experience from which the data is collected; (2) Determine the IEP team dynamics which inform the IEP/ITP programming; (3) Determine which coping resources are being accessed and which quality of life indicators are being met through the phases of transition and the IEP/ITP. Coupled with experientially developed

presumptions, I argue that each of these areas of the transition experience directly impacts familial perceptions of positive transitions and team dynamics.

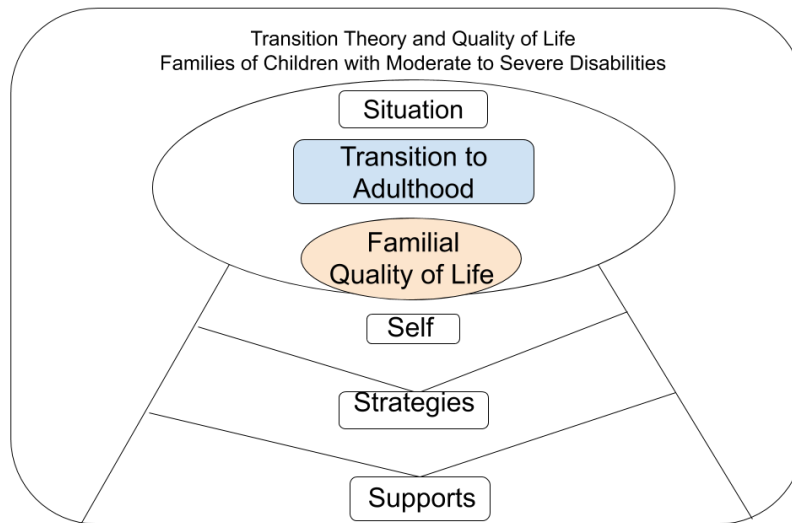


Figure 3.1 Special Education Familial Quality of Life through Transition Framework

The quality of life through transitions framework assisted in analyzing interview data collected from the parents of students with moderate to severe disabilities going through the transition to adulthood. The goal of using this framework was to identify themes and understandings of transition IEP meetings based on the narrative of parents' responses to interview questions. Specific points in the theory of transition, coupled with the quality of life indicators as a reference to how parents experience transitions into adulthood for their child, positioned and bolstered data that revealed codes in the open-coding process (Creswell & Poth,

2016). Initial open-coding employed the use of MAXQDA software to identify themes and organize data into categories. After initial open-ended coding, I reread the transcribed data to further pluck narratives and locate them into the broader and more specified categories through focused coding (Emerson et al., 2011). After rereading the data, I used member-checking strategies as a means to clarify my understanding of the participant narrative. Peer debriefing was used throughout the analysis process which occurred with professionals in the field of special education, as well as other scholars. Member-checking and peer debriefing used in data analysis are effective methods for reducing “noise” and increasing validity in qualitative, textual descriptions of data (Maxwell, 2013). In phenomenological research, focusing on the meaning and organic essence of the families’ experiences helped me move from coded data to themes. My goal was to develop a holistic and descriptive account enveloping the entirety of the experiences of participants (Moustakas, 1994).

Positionality

As an Education Specialist in the field of education and research, and an advocate for the quality of life for individuals with disabilities and their families, I realize that my position could have influenced the lens from which I collected and analyzed data provided by participants. According to Creswell and Poth (2016), “Researchers recognize that their own background shapes their interpretation, and they “position themselves” in the research to acknowledge how their interpretation flows from their own personal, cultural, and historical experiences” (p. 24). Recognizing that I am both a practitioner in a school district and an advocate for students with disabilities, I know that my interpretations of data may have been influenced by my experiences in the field, including in transition meetings. I am mindful that phenomenological research foregrounds epoche, or suspension of judgment, in order to gain a fresh perspective void of

possible presuppositions interfering with the research process (Moustakas, 1994). Epoche bracketing provided me the opportunity to envision the transition phenomena clear of opaqued experiential understandings (Moustakas, 1994). In order to mitigate the possibilities of swayed data, I reflected upon and bracketed my experiences to the greatest extent possible. I also used crystallizing strategies of member checking and peer debriefing during the processes of collecting and analyzing data.

Ethical Considerations

Minimizing risk to participants of this study is at the forefront of ethical considerations when conducting any research. Esterberg (2000) states that two issues of particular concern to the researcher are confidentiality and consent. I provided credence in confidentiality for all participants through detailed explanations of the study purpose and willingness to provide answers to questions and concerns. Pseudonyms were used through each step of the research process to conceal the identity of participants. Schools and districts were identified solely through pseudonyms. Interviews were conducted virtually in a secluded room with no possibility of distractions or interruptions from the location of the researcher. Notes, recordings, and transcriptions were placed in a locked drawer in my home and on my password-protected and locked computer.

Finally, participants signed a consent form (Appendix C) that outlines potential risks to the volunteers. Participants were given the option to remove themselves from the study at any point in time. It is my hope that participants felt secure with the safeguards I have implemented, as evidenced by consent to this important study surrounding the quality of life for family members' experiences during IEP/ITP meetings.

Limitations

Employing qualitative research methodology to address the research questions in this study was the best approach to garnering family voice surrounding transition. The use of qualitative research methods has its limitations, including the inability to generalize to the population (Maxwell, 2013). Qualitative research can inform theory and practice, but generalizability is not the goal. Findings from this study are not likely generalizable to all special education transition experiences; however, the findings will enhance understanding of how IEP/ITP teams are perceived by families during life-course transitions.

The research was also contingent on the willingness of participants to vulnerably share their transition experiences. Further compounding the building of rapport before the second interviews, is the fact that COVID-19 restrictions meant that all interviews had to take place in a virtual environment. A virtual environment is not as conducive to producing trusting relationships, as there is an inability to properly read body language and oft-times technological or other barriers impede the ability to connect on an empathetic level. The limited time frame of this study in correlation to participant criterion could equate to a study that is phenomenological by nature. All of these factors, along with researcher positionality, should be considered as potential limitations to the study.

It is highly recommended that this study be replicated during a time when a pandemic is not impacting the entire world. The shift from in-person learning and meetings to virtual environments and unprecedented pedagogical practices greatly changed the manner in which students with disabilities and their families experienced the transition from secondary education to adulthood. These external variants shaped results for applicable knowledge through the typical transition of students to adulthood. While some practices and protocols remained intact

for transitioning a student to adulthood, teams' visions and planning were interrupted by the pandemic; ultimately, the added anxiety of an uncertain future for the world in terms of physical health compounded transition stressors for families.

Chapter 4: Results

The purpose of this study was to describe and analyze the experiences and perceptions of parents who have children with moderate to severe disabilities as they go through the transition from high school to post-secondary programs and services. Parent involvement is the most critical component of the IEP and IEP team, and it is mandated by the reauthorization of IDEA 1997 and 2004. Special education planning and goal creation are meant to be held in collaboration with the IEP team; parents' and students' voices should be the most prominent in each meeting. Nine parents of students with moderate to severe disabilities who are currently in a public adult transition program were interviewed about their experiences of perceived support or lack of support from IEP teams and meetings throughout the transition process. This chapter presents the findings of this study. First, I describe the parent participants, their familial transition situations, and introduce the participants in this study. Next, I discuss the emergent themes in relation to the research questions.

Participant Profiles

The participants consisted of the parents/family members of nine young adult students attending (either currently or in the past 3 years) a San Diego County public school adult transition program, ages 17-24. To maintain their confidentiality, pseudonyms have been used to describe them and their children. The following participants represent the students and families interviewed from the public school adult transition program: Mr. Grier (father), Matthew (student), age 18; Alice Patton (mother), Russ (student), age 19; Mrs. Ferguson (mother), Sasha (student), age 21; Marta Lopez (mother) and Eva (sister), Alfredo (student), age 20; Lisa Gershin (mother), Colby (student), age 23; Christy Moreo (mother), Ryan (student), age 19; Andrea

Martinez (mother), Maria Martinez (grandmother), Oscar (student), age 19; Tracy Simmons (mother), Maddie Simmons (student); and Kim Morales (mother), Eric (student), age 19.

The profile of each of the participants is described below. The participants are all parents of students with moderate to severe disabilities who have recently transitioned to post-secondary life; however, they differ in terms of their children's special education designation and transition point in time. Each participant shared unique experiences through the school years of their child and the lens of both a parent and advocate in special education. Undoubtedly, transitions were some of the greatest times of stress for these families. Inflection, tone, and language within the data slightly changed based on the topic of discussion. Overall, the data revealed that the participants truly care about their children and their children's success and happiness in life into adulthood.

Mr. Grier, parent of Matthew Grier. Mr. Grier is a white, married male who has worked for over 20 years for the school district all of his children have attended. He is the father of Matthew Grier, an 18-year-old young man diagnosed with autism who graduated with a certificate of completion from a southern California high school in June of 2020. Both parents are very involved in Matthew's life; but, since Mr. Grier works for the school district, he tends to be more involved with the IEP teams. Mr. Grier travels to different campuses throughout the school district, so he often checks on his son during class and asks teachers questions when he is on campus at his son's school. Mr. Grier was excited to share his story about IEP teams and transitioning to adulthood because he truly cares about the district, school, systems, and students with special needs. Mr. Grier's wife also works for the school district but does not have as much flexibility in her ability to attend meetings and check on her son throughout the school days.

Mr. Geier's son, Matthew, lives at home with both of his parents and his older sister. Matthew's

older sister, Karen, goes to the local community college and works part-time. Matthew is also taking classes at the community college, while he is training and learning at the school district's adult transition program. COVID-19 and the global pandemic have greatly impacted this family and their children's progress in life. Matthew has regressed, especially in the domains of social inclusion and emotional well-being, since he was learning solely via a virtual platform for over a year. Mr. Grier remains a steady advocate for his son by speaking up when he needs more services (such as extra counseling or therapies) or a change in his IEP.

Alice Patton, mother of Russ Patton. Alice Patton is a white, married woman who works part-time and runs a small business. Mrs. Patton is the mother of 19-year-old, Russ, a young man with down syndrome. Russ went through the same school district for his entirety of elementary, middle, and high school after attending kindergarten at a neighboring school district. Mrs. Patton is very involved in Russ' life, and she has always been a stay-at-home mother for her family and Russ. The Patton family consists of Mr. and Mrs. Patton, and Russ living together in a home; Mr. and Mrs. Patton also have three adult grown children who live in different cities. The Patton's have lived in Southern California since Russ started in special education at the age of three. In fact, Mrs. Patton shares how the early childhood programs for children with disabilities in the Orange County, California area were strong and assisted in supporting Russ and his family as they entered into the public education school system. Mrs. Patton is an avid advocate for Russ; she consistently plans her life tasks around the needs of Russ. Mr. Patton is also an advocate for his son, and he has assisted in coaching special needs sports teams, as well as attending Russ' IEP meetings.

Mrs. Ferguson, mother of Sasha Ferguson. Mrs. Ferguson is a single, white mother with two adult daughters currently living at home, ages 21 and 23. Her youngest daughter,

Sasha, is in her final year of the adult transition program, as she will age out of the publicly mandated program at the age of 22. Sasha is severely impacted by her disabilities, which include cerebral palsy, diabetes, and CMV (Cytomegalovirus). Sasha is non-ambulatory, nonverbal, and she requires 24-hour care to ensure her diabetes is under control. Sasha's father is not in her life, but Mrs. Ferguson uses Regional Center funds to hire a respite worker for about 20 hours a week. She works from home and provides for both of her daughters. The experience of being a single mother to two, with one child having severe disabilities, was not always an easy road for Mrs. Ferguson. She gained confidence and strength through the years of advocating for Sasha and her needs at home and school.

Ms. Ferguson did not suspect that Sasha had any disabilities until she was not meeting her developmental milestones in her first year of life. During her pregnancy, Ms. Ferguson fell extremely ill during the second trimester, which was diagnosed as Congenital Cytomegalovirus (CMV) only after Sasha was tested for various developmental disabilities. CMV caused Sasha to also be born with profound hearing loss and has impacted her cognitive and functional abilities. Cerebral Palsy and type 1 diabetes further complicate Sasha's physical health issues and needs. Not having Sasha's father in the picture meant that Ms. Ferguson took on the role of a parent of a child who needed round-the-clock care as a single parent. Overall, Ms. Ferguson has always felt quite empowered as Sasha's advocate and speaks up during meetings or in other times of concern.

Marta and Eva Lopez, mother, and sister of Alfredo Lopez. Alfredo is a 20-year-old young man who has autism spectrum disorder and is impacted in his functional and daily living. He is from a loving Latino family of six, consisting of Alfredo; his mother and father; his older sister, Eva, who is currently in her last year of college; his younger brother (lower elementary),

and a younger sister (middle school). This family of six resides in a 3-bedroom apartment where Mr. and Mrs. Lopez, as well as Eva, work together to provide for their family. Alfredo is unable to be left alone, as he could wander or hurt himself with an inability to functionally communicate with most people outside of his family. Alfredo is the only family member with a disability, and those in his home are very tolerant and supportive of Alfredo's unique abilities and behaviors. Eva shared that when their family has gone to Mexico to visit other relatives, there was not a sense of support. Marta and Eva both shared that in Mexico, Alfredo stays in a relative's house with little to no interaction with the community. They have felt a sense of judgment from the residents of the small town that the Lopez's originated from in rural Mexico. Moving to the United States when Alfredo was young was the best decision they made for their family in their perspective.

Marta's first language is Spanish, and she has always required a translator to participate in IEP meetings through Alfredo's years in the public school system. It was during Alfredo's fourth to the fifth grade school year that Marta saw exponential growth in her son, and according to her, it is because of the ambitious goals his teachers had pushed for Alfredo to have in his IEPs. Understanding the physical location of schools Alfredo has attended and meeting his teachers have always been of value to Marta in building trust and a strong relationship with the district. Mr. Lopez has not attended all of Alfredo's IEP meetings, and Eva joined as a part of Alfredo's IEP team when she reached high school. Overall, the Lopez family has had great experiences within the school district; however, during their interviews, there were certain areas of concern that came up regarding their experiences with IEP teams.

Lisa Gershin, mother of Colby Gershin. The Gershin family consists of Lisa and her husband, as well as two children, Colby and Katherine who live in a southern California suburb

of San Diego. Lisa is a white, middle-aged woman who works in the field of special education as an instructional aide in the district her son, Colby, has attended since he was three years old. Colby is severely impacted by autism spectrum disorder and has very few communication skills for life outside of his home. Colby's family is very supportive of Colby and ensures that he lives a socially active life in their community. In fact, many residents of the community know Colby which comes as a surprise when Lisa sees so many people interacting with Colby in the community.

Prior to having Colby and learning of his autism spectrum disorder diagnosis, Lisa worked in the dentistry field; however, it proved difficult for Lisa to continue with her career and be a caretaker and advocate for Colby. When Colby was young, Lisa decided to hire a special education advocate from Orange County, which is where Colby was born and the family resided until he was two years old. The advocate was expensive, and the family decided to be Colby's advocate themselves to improve their quality of life. Lisa feels as though they were faced with obstacles based on IEP team decisions and untimeliness of support. Her biggest concern regarding the lack of support through the years was the latent integration of augmentative and alternative communication (AAC) support for Colby. Lisa strongly believes that if Colby had access and support in learning to use AAC devices before middle school he would be further along with his communication and life skills. Academic inclusion was also an area of concern for Lisa's understanding of Colby's education journey. She faced unsupportive classes and teachers until eventually, a compassionate teacher included Colby in her classroom during his mid-elementary years. A lack of programmatic integration between general education students (and their families) and special education students (and their families) left Lisa believing that those in the life and careers of special education should push for more social inclusion through

the school systems. Colby is now 25 years old and attends an adult day program for adults with disabilities where he is happy, and the family is content with his program.

Christy Moreo, mother of Michael, Ryan, and Cole Moreo. Christy, a white woman in her early 50s, is a prominent member of the Autism Society of San Diego, and all 3 of her sons have been diagnosed with autism spectrum disorder (ASD) and qualify for an IEP in special education. Christy knew her first son, Ryan, was different from neurotypical children, although her ex-husband and ex in-law's disagreed at the time until he got his official diagnosis around 3 years of age. In retrospect, Christy had a suspicion that her boys' father was also on the autism spectrum; unfortunately, Christy's ex-husband passed away in December of 2020 leaving behind his 3 boys with ASD. Christy has been divorced from her sons' father for over ten years. Although Christy was her children's primary caretaker, her boys did spend time and holidays with their father. Ryan lost his father during his first year of adulthood in an adult transition time. Christy states that Ryan has asked about his father and had times of grief, but they have remained strong as a family, which also includes the boys' stepfather.

Christy has always been a strong advocate for her children, and the family moved to southern California just before Ryan's fifth birthday to access better resources for him. In Washington state, Christy says that the Pre-Kindergarten experience was excellent, but when Ryan went through Kindergarten there she was troubled with their inability to support her son. To increase their quality of life, the family chose to move within the boundary of a district known to have a quality special education department. Christy's other two sons have since been in the same school system; however, they have required special placements at non-public schools for behavioral concerns. Some of the non-public school placements proved to negatively impact Christy's perception of IEP teams.

Transitions have been a way of life for this family as they have journeyed through many program placement changes for Michael and Cole. Ultimately, Christy is extremely content with the IEP teams Ryan had through the years. She chose to share information regarding Michael's and Cole's experiences to further show how IEP teams and placements can be extremely ineffective in supporting a healthy quality of life for a family.

Andrea and Maria Martinez, mother, and grandmother of Oscar Martinez. Andrea is a single, Latina mother of three children living with, and helping to support, her mother; the five of them currently reside together in a three-bedroom apartment. Maria, Andrea's mother, has been a part of the children's lives since birth. Oscar is a 20-year-old student currently attending a public school adult transition program in the Southern California region where he resides with his mother, grandmother, older sister, and younger brother. Oscar was diagnosed with ASD at the age of three when his mother suspected he was developmentally different from his older brother. Andrea is frank about how uninvolved Oscar's father has been in his life. Andrea's father who participated in helping in the family unit passed away when Oscar was three years old, further compounding the stress and barriers to accessing support and resources for Oscar.

Maria, Oscar's grandmother, was his primary caretaker until high school and she has attended every one of his meetings. Maria's first language is Spanish, and she has required a translator at all of Oscar's IEP meetings. Cultural differences and misunderstandings within the IEP and the teams have made it difficult for Maria to feel like she had fully participated as a member of Oscar's IEP teams. Once Andrea, Oscar's mother, became more involved starting during his high school years, they felt more empowered as a family unit when attending meetings. However, oftentimes, both Andrea and Maria feel as though they do not know the

right questions to ask during meetings. They feel as though they are not fully advocating for Oscar without being given the proper information and resources from the IEP teams. These feelings of inadequacy in advocacy have slightly dwindled as Oscar has transitioned into adulthood, but the family feels as though with the right support resources could have already been in place for Oscar.

Tracy Simmons, mother of Maddy Simmons. Tracy is a white, married mother of three children who works as an instructional aide at the local high school where all three of her children attended school. Maddy is a 20-year-old young lady diagnosed with Down syndrome. Maddy is Simmons' first born child, and she has two younger brothers, ages 19 and 16. Her oldest brother is away at college, but he remains a consistent part of the family life. He has always taken care of his older sister and protected her from the hurtful words and actions of others. Maddy's youngest brother is currently still in high school. Maddy lives at home with her mother, father, and younger brother. Before working as an instructional aide, Tracy was a stay-at-home mother and part-time school substitute since Maddy was born, as they knew her diagnosis prior to birth. Tracy and her husband were hesitant to have more children after having Maddy but changed their minds very quickly within the first year of Maddy's life.

Tracy redirected her life path once Maddy was born; before Maddy's birth, Tracy was a graphic designer. Even with Maddy in her life, Tracy has found ways to put her graphic design degree into action. She is very involved with the regional Down syndrome society, and she enjoys planning and creating meaningful fundraising events; Tracy also designs for the society's website and flyers for events. Tracy ensures that her daughter has a full and meaningful life by allowing Maddy to go out with friends, have a boyfriend and go on dates, and foster a healthy lifestyle by playing on special sports teams. For the Simmons family, life got hard when Maddy

was a junior in high school when she had a massive stroke. The family experienced two deaths in their family in that same year. Maddy's stroke set her back functionally, socially, and academically, but she was able to have brain surgery which proved to be of great benefit to improvement in these areas. She is now thriving in an adult transition program and volunteering at a farm filling her days with continued learning and growth.

Julie Morales, mother of Eric Morales. Julie Morales is a white, mother of six children ranging in ages from 8 to 24 years old. She has been a stay-at-home mother for the last 24 years, but she has recently started working from home for a government agency doing data entry. Julie's husband, a Latino man who went to high school with her, has supported all of his children and his wife through the years as a father and provider to his family. Eric is one of the middle children and has an older sister, an older brother, and three younger brothers. The family of eight all live together in a suburban area of San Diego County where Eric has attended the same public school district for the entirety of his formal education. Eric was diagnosed with Down syndrome when he was born and entered the school system at the age of three years old. Julie has always felt as though if there were problems at school, she could always talk to the case manager/teacher to rectify or assist with the problem. During his middle elementary years, Eric was struggling with staying on task in the classroom and disrupting other students. Eric's teacher initiated a volunteer position for Julie in Eric's classroom to help support him through those tough years. This initiative of trust and support paved a path and fostered a strong perception of support from the IEP team for Julie, Eric, and her family. Through his middle school years, there was one general education coach who took Eric under his wings and even assisted with introducing him to becoming a member of a strong basketball team for children and young adults with special needs. Eric excelled in basketball and went on to join the wrestling

team by his junior year in high school. Eric has led an active social life with the help of his family supporting him every step of the way. He has a girlfriend who he has been dating since his freshman year of high school, and he goes out with friends a few times a month.

Julie believes that the only thing she could have done better for Eric was to push for more inclusion in the academic settings during his K-12 years; she also understands that many teachers have pushed for inclusion, but the process of full inclusion for students with moderate to severe disabilities at that time was a fairly new concept and not fully integrated into the schools. Julie is extremely proud and happy about the amazing progress Eric has made including recently interviewing for part-time jobs.

In sum, the participants in this study represent a range in terms of their diagnoses, needs in special education, family configurations, and phase of transition for their adult child with disabilities. The families who participated in this study were open, candid, and eagerly descriptive throughout the interview process. Each participant passionately engaged in describing their experiences. Some participants became emotional as they divulged the ups and downs of having a child with moderate to severe disabilities. Their stories illuminated the strengths and weaknesses of the public school special education programs. Below each description of emergent themes are examples from the data exemplifying the intertwined stories revealed by these families who have gone through the transition to adulthood for their children with disabilities.

Themes in Parent Perceptions of Supportive IEP Teams during Life-Course Transitions

The themes that follow result from the analysis of the participant's participation in

the special education transition IEP team and meetings as parents of a child with moderate to severe disabilities in San Diego County. The parents of students with moderate to severe disabilities who have transitioned their student out of public high school and into an adult transition program have perceived areas of strength and growth, as well as pertinent obstacles for a seamless transition and better quality of life for their families as it pertains to IEP meetings and teams. These thematic areas directly pertain to the research questions of this study. To recap, research questions and correlated themes are as follows:

1. How do parents of students with moderate to severe disabilities experience the transition of their child to post-secondary life when supported (or not supported) by public school IEP/ITP team members?
 - a. How are QOL domains and indicators being met (or not met) for students and families experiencing the transition to adulthood?
2. How do parents of students with moderate to severe disabilities perceive IEP teams prior to and during their child's exit from secondary schooling in the transition to adulthood?

Below each description of emergent themes are examples from the data exemplifying the intricate stories revealed by these families who have gone through the transition to adulthood for their children with disabilities. Participants describe their experiences from each stage of transition theory, from approaching to assimilated transition, in the years of having a child with special needs in the public education system. Interestingly, different types of transitions throughout a student's academic career were illuminated by parents and guardians as they provided information regarding their child's transition to adulthood. Transitions of all types impacted students and families and their experiences with IEP teams. Prior transition

experiences for these families reflect similarly in their stories of the transition to adulthood for their children. Themes arising from the analysis regarding these experiences included:

- COVID-19 Impacts on Transition and Family Quality of Life
- Perceptions and Use of Coping Resources through Transitions: Self, Strategies, and Supports
- The Influence of Social and Academic Inclusion on Family Perceptions and Quality of Life
- Personal Development, Self-Determination, and Emotional Well-being for Coping through Transitions
- Interpersonal Relationships for Family Quality of Life Transition Planning
- Rights, Well-Being, and Broken Trust in Family Perceptions of School Team Support

COVID-19 Impacts on Transition and Family Quality of Life. The most prominent theme for parents in this study was the impacts the COVID-19 pandemic had on their whole transition experience as a family. This global pandemic brought new fears and worries regarding their family's physical, material, social, and emotional well-being. Anxiety surrounding everyday life and the future directly impacted how parents perceived their child's transition to adulthood during unprecedented times. The direct impacts of the COVID-19 pandemic altered many aspects of family life, including how families coped with transitions. The families' understandings and use of self and strategies to cope were modified as families undertook more time at home with their children and navigated an uncertain world. Families had to intensely integrate technology into their lives for their children to access school and classes. The strain of a newly created reality left parents scrambling to care for their children, while many parents worked from home or had other stressors concerning their means of financial well-being because

of the pandemic. Families who were transitioning their children with disabilities into adulthood and adult transition programs were left feeling isolated and confused about the process and what would come next for their children. Data revealed parents recognized the uncertainty and under-preparedness of the IEP teams as they also carved a path for their students to access adult transition programs; with this recognition came a grace for the teams and an understanding of the difficulty of the times. For example, Julie discussed how she experienced the transition of her son, Eric, to the adult transition program:

Well, yeah. Yeah. I'm trying to even remember. That's a really hard one because everything was so weird. I just don't think it... I don't know if there could have been more communication and I just didn't get it. But yeah, we didn't have the going over to the school. We didn't have any of that. I don't even remember how school started, like how I got the information, how he got that information. I don't remember- ...It was so weird.

The physical transition and in-person transition meetings never really happened as they would have in a traditional time prior to the pandemic. The impacts of not engaging in social and academic stimuli at school took its toll on students with disabilities. Most curricula at their basic level are difficult to teach online with no prior training, let alone assisting students with disabilities trying to obtain everyday functional life skills. Christy Moreo found this to be true when she attempted to provide access to the virtual teaching and curricula for her son, Ryan, before and through the beginning of his transition to adulthood:

Everybody I feel like has done their best. The year that we were remote was rough. I don't know how you could possibly do this program remotely effectively. You can't teach somebody life skills by Zoom. So, I just kind of, I feel like we were mostly just killing time when we were at Zoom. But I mean, I don't see how, what else you could do.

Christy's realistic perspective on the difficulty of teaching students with disabilities during a global pandemic made it easier for her to cope with having three sons with autism at home 24 hours a day through this pandemic. She discussed this with a local newspaper and shared

strategies of how to get through this new role as a teacher in their homes with other parents who have children with autism. Ryan did not receive as many in-depth curricula and transition experiences as Christy would have liked for him, but she stated, “So, I mean, you could only do what you could do.” Christy was accessing her own coping mechanisms and strategies as Ryan went into transition through modifying her perspective on the perceived and actual transition experience. COVID-19 forced families to rely on one another by forcing a change in their daily lives as a family unit.

The impacts of COVID-19 on students across the world made transitioning for all students difficult during a novel time of uncertainty. Many families experienced a lack of schooling and a full understanding of how transitions in life can be seamless when the proper supports and strategies are in place. Alice Patton recognized that while going through the transition to adulthood, her son, Russ, would not be able to have an authentic experience in an adult transition program until in-person teaching and learning returned to public school districts. At the time of the study during the pandemic, Alice was still attempting to understand the adult transition program and how it might be of benefit to her son’s education stating,

That's a tough one because of the pandemic, you know, he hit the adult transition program right at a time where it was not normal, and I really don't know what the program was really gonna be like, because he didn't really experience it the way he should've, I think, the first year. But just the few weeks that he's been back, I can see a difference in him.

Unfortunately, families who had students transitioning to adulthood during this pandemic were “cheated” of a truly seamless transition. Mr. Grier had plans for his son, Matthew, after high school; he had a vision for what the program would look like for his son impacted by autism spectrum disorder. He was passionate about creating a post-secondary life for his son, and he stated, “you know, I think with all the intentions, all the best pieces were laid out. I had a pretty

decent game plan for how it would all look before COVID hit.” Mr. Grier had a plan to have Matthew attend a local community college in the morning, go to lunch with him, volunteer in the art class at the local high school, and continue to run with the track team after school. This plan was interrupted when all schools went to virtual learning online once the COVID-19 pandemic hit the nation. Matthew still attended college, but the plan did not look like Mr. Grier wanted it to for Matthew. He does see how it all worked out after his son transitioned to adulthood and feels that Matthew has benefited from online learning; Matthew is adept with technology and passionate about learning, yet he struggles with the social aspects of school. Online virtual learning worked for Matthew and the Grier family even though they resisted this change at the start of the pandemic. Mr. Grier was able to modify his perception of a quality education for his son through self-determination and has assimilated this change into their lives; thus, he has been utilizing coping strategies through his son’s transition to adulthood.

The pandemic shifted life for everyone around the world, and as hope is a large part of parenting a child with special needs, this shift illuminated new learning for parents bringing them more hope for their child and the years ahead. Eva Lopez, the sister of Alfredo, explains how she has a completely different perspective on how special education classes benefit her brother after spending time with him during his online classes. She explains this illumination through her experiences with Alfredo:

And that's, like, for us, as parents, or us as guardians, um, it was so amazing. Like, that's just one pro that came out of the pandemic that we are actually here in the classroom, while he's in the classroom. And we're acknowledging and listening to everything that he's doing and he's learning. And so that's one thing that I saw as a pro.

The entire family was able to take turns assisting Alfredo with his online learning when school was exclusively in a remote format. This new experience for the family has deepened their

relationship with Alfredo and informed decisions for him as he entered into the adult transition program. This made for a smoother time period for the family as Alfredo neared his transition from high school. The unknowns of how a life skills curriculum could benefit Alfredo were better understood and practiced within the home. Eva and her mother, Marta, had a sense of comfort after watching his online classes and visiting the site of the adult transition program where Alfredo would attend school for the next four years. The fact that learning could be changed back to remote and online was not of huge concern for this family, as they knew that working together would bring Alfredo closer to his goals, either way, he attended classes.

Albeit a strenuous time for family units, families became more reliant on one another throughout the pandemic. Times of uncertainty, such as a pandemic or life-course transition, can bring families closer. Mr. Grier and his son were able to take a road trip to Yosemite together. Other families, including the Patton's and the Simmons', visited family across the country. Leaning in on each other and taking small trips for family bonding, just as Christy Moreo and her sons found out, gave them time together, which rarely happened in pre-pandemic times. They were able to spend time together visiting Disneyland and other theme parks with smaller crowds, which is beneficial for people with an autism spectrum disorder.

There is no question about the impact the Covid-19 pandemic had on each family's experience of the transition to adulthood for their child with disabilities. Access to a quality life skills curriculum was nearly impossible, schedules were interrupted, and families were left navigating an unknown world of online learning, stalled and altered plans, and uncertainty about the future for themselves and their children. As Christy Moreo stated, "I think we all have a new appreciation from being able to go places and do things." Perspectives about all aspects of life were questioned, changed, and left in states of undoneness. Gratitude, small steps forward and

positive thinking kept families going in times of devastation; perceptions of who families' are, both individually and collectively as a family unit, were rebuilt through a novel time.

Perceptions and Use of Coping Resources through Transitions: Self, Strategies, and Supports. The experience of transitioning a student with disabilities to adulthood begins with families' perceptions of self through the process. Self is one of the four S's within Schlossberg's (1981, 2011) transition theory. The self within transition theory refers to a family's demographics, including health, culture, socioeconomic status, as well as individual and collective identities. Self is one of the four coping resources within the transition theory which puts the experiencer of transitions into a place of autonomy. It is the outlook, optimism, resiliency, and spirituality of self which often guides how people will experience transitions (Schlossberg, 1981). While portions of self are static within the individual family members, the plasticity of the family to be reliant on each other for support and strategies for coping has the potential to alleviate stressors through their child's transition to adulthood.

A family's outlook and use of strategies have a direct influence on their experience with IEP teams and their child's life-course transition to adulthood. Strategies defined within Schlossberg's transition theory include information seeking, direct action, inhibition of action, and intrapsychic behaviors (Anderson et al., 2011; Schlossberg, 1981). Families in this study have utilized these strategies within their family culture and daily life on varying levels. Participants often discussed how members of their families accessed strategies as a means to manage stress, control the meaning of the circumstances, or modify the transition itself. Lisa Gershin, the mother of 24-year old, Colby, stated that:

And high school was more life skills, same with like middle school, so that was... I mean, you kind of as a parent, it's like are they going to take a path of an education or are they going to the path of the life skill, and I, I realized he was going to be the life skill kid.

Lisa was able to modify her thinking and emotions related to herself and her son's life course in order to provide greater quality of life, which in turn, altered the whole family's perspective of transitions in special education. Not only did the pressures of attempting to guide her child with autism through an academic career wane from the family's concerns, the path she knew he would take meant that she could reflect the skills being taught at school into their home life. This switch to a functional focus for Colby's educational journey provided comfort for Lisa as she participated in meetings and prepared Colby for adulthood. She explains how she accepted and assimilated this change in focus:

He wasn't going to talk, he wasn't going to read, he wasn't going to do math, so it was like, okay, well, I need him to take care of himself when I'm not around that type of thing, or if something happened he had to go to a group home. So that was all good, but, um, it was definitely, I would say, felt more comfortable and more like I was one of them [a contributing member of the IEP team] in high school.

After Colby's program switched to a focus of functional skills, Lisa began to feel like she was a louder voice in his IEP team meetings.

Other families quickly identified their roles as advocates for their children and felt confident enough to change courses of action to benefit their children when necessary. With a sense of empowerment, strategies are employed by families who seek knowledge and take steps to better their child's education. Christy Moreo knew that the services her son, Ryan, was receiving when they lived in Washington state were not sufficient for his growth and progress in life.

I was hiring my own therapist and training them myself, which is probably why his ABA was much, I feel like was much better than the ABA that you get here, where it's like they go into a data bank and be like, "Oh, here's your next goal?" Like, no, that's not personalized to my kid. We just figured out what worked for Ryan and we made it up as we went along.

Christy learned the ins and outs of the public systems in place for people with autism spectrum disorder trajecting her level of concern. The Moreo's moved to southern California solely to place Ryan in specialized programs without long wait times for admittance. Information seeking advanced Christy's ability to feel comfortable with and participate in IEP meetings. Her actions ultimately positively impacted the family as transitions occurred with all three children through their years in special education programs. As Mrs. Moreo discussed not only the transition to adulthood for Ryan but also for her sons Cole and Michael, she described how she has modified her perception of transitions in special education: "Each one that you're in is less stressful, because you've done it a few times." Perceptions of herself, her family, and her children's paths in life changed through time; this change brought a positive mindset to the table for the IEP and transition meetings.

Andrea, the mother of Oscar, used perspective-taking to feel more secure with how life is for their family living with someone who is on the autism spectrum. She found solace when she realized that the life activities of neurotypical people are accessible to her son with certain adaptations or modifications. She relaxed her face in comfort while describing a scenario in her life that gave her hope for Oscar's future:

We had neighbors or well, we still have a neighbor, who were both disabled and they were married. And that was for Oscar, the first time I think, he ever met a couple with disabilities, being married, living on their own, having an apartment. But they still had assistant. They have assistant aides that come and stay with them every eight hours. So they have shifts. So he would have this help and he would, he was watching this.

After seeing for herself that life still has great joy in it for people with disabilities, Andrea was better able to cope with her reality. Coping strategies such as perspective-taking increase the quality of life for families as they reframe and reimagine their lives while raising a person with impacting disabilities.

Moments of discomfort also occurred in the realization of life's circumstances, which often led families to readjust expectations and release control of situations. Mrs. Ferguson had to modify her thinking of who would be taking care of her daughter, Sasha, while she was in public school. Coping with the realities of having a child with such significant disabilities can take a toll on the primary caretaker of the child. Mrs. Ferguson has not always had an easy time relinquishing care of her daughter during school days, which is almost a daily transition.

So she, and for me, you know, she's a very specialized person that you need to know and it was like just throwing her to a bunch of people that she didn't know. So it was very uncomfortable for me. I was very, um, not worried because ... I mean, what's the worst that can happen?

Metacognitive practices, such as overcoming fears with thought, are coping strategies that families use to create more seamless transitions, especially the transition to adulthood.

Access to supports and strategies, which directly influence a family's perception of the IEP/ITP team during times of transition, can be made more available when the team in its entirety is working collaboratively to inform students and families of processes in the IEP. The exchange of communication within the IEP/ITP meetings, both expressively and receptively, is often the most important aspect of creating a solid program and transition. Alfredo's mother, Marta discussed (via a translator) the explanations the IEP team provided her regarding his goals.

They always have a reasoning and they always had... Alfredo's potential in mind. And that's what she [Marta] saw that like, the, the best way that she felt supported was at, when the teachers explained his potential and the why of whatever things were going on, and that they would always have time to explain everything to her. Like, "This is the way we're gonna work things out. This is the way we're gonna do it." And she always felt like she was in the loop and that's what she appreciated the most.

Once Marta understood the purpose of the IEP and ITP goals for her son, she was able to have greater trust in the team. Her reception of the explanations and willingness to understand the

information benefited the dynamics within the team; most importantly, it enabled the team to create a more seamless transition to adulthood for Alfredo.

How a family perceives itself as a unit, and individuals within that unit, will often influence their reactions and actions surrounding major life transitions. Understanding the transition to adulthood as a situation the entire family goes through, while also having discernment about self, leads to increased positive perceptions of IEP teams; positive perceptions improve the chances of family members accessing transition supports. When supports and strategies are used by families, the transition to adulthood becomes more seamless for the children, families, and entire IEP teams.

The Influence of Social and Academic Inclusion on Family Perceptions. Social and academic inclusion greatly influence a family's perception of a supportive IEP team and community. Families are more likely to perceive an IEP team and a community as supportive when their child, which often means the family as well, is included in academic and social scenarios where there are typical students and families. While most participants mentioned inclusion of some form as either a strength or weakness within their child's school programs through the years, some parents covertly expressed a feeling of exclusion even within their own IEP teams. Transition experiences were uncomfortable for parents who felt uninformed based on exclusionary actions or practices. Inclusion has been increasing for students with special needs, yet there is still a lack of equity for these students today.

Mrs. Simmons, Maddy's mother, expressed her desire for education systems to be more inclusionary in social and academic settings. She recognizes that there have been great strides toward increasing inclusion in the schools, but believes that there is room for improvement. Her experiences were positive when she did push for inclusion; however, the reality for this family is

that inclusion was not fully understood nor practiced when Maddy was in her early educational career.

I feel like now it's a much bigger deal that parents are pushing for inclusion than it was back then. And 17 years ago it was... People would say it, but I don't think it happened as much. So it was a little bit more difficult to do.

Families often equate successful transitions to how inclusive a student's program has been on an academic and social level. Many times the familial quality of life during times of transition is viewed as positive or negative based on past experience with IEP teams and the school community. Inclusionary practices perceived as positive by families happened within varied contexts of school and the community as a whole. Many times, when team members or other members of the community recognized or included students outside of school hours, families increased their positive views of schools and IEP teams. Oscar's grandmother, Maria, described how even when a coach and former bus driver from school who worked in her apartment building recognized Oscar making her feel included in the community for her family.

...right here where we live, they send a notice that somebody coming to see, the apartment, whether we need or is something broken, or whatever. ...So, he [came] in and he [was] walking in the hallway and [saw] the pictures like him and he [said], I know him. When he told me, I remember, "Oh, this man," he said, "I remembered you too. I'm a coach here in the school. And then I drive in the bus."

Maria lit up with a smile as she told this story and went on to talk about how great it makes her family members feel when Oscar is known in the school and community.

Mrs. Ferguson, the mother of Sasha who is very severely impacted by her disabilities, felt appreciative when community members recognized Sasha in the community.

[Going out prior to the pandemic] people would know Sasha more than anybody else in our family. Like they would see her out and speak to her, and that was kinda nice. I, I definitely appreciated that.

Lisa Gershin, the mother of Colby who is severely impacted by autism spectrum disorder, knew to increase her family's quality of life she had to expose her son to the community through social inclusion as much as possible. She proudly explained:

I always took him places when he was young. I never kept him at home or, you know, hidden away, so. And the community, everybody knows him, because I've always done that, and, yeah, so that was a cool experience for him.

Lisa fosters strong interpersonal relationships for her family and with community members.

Being an employee in the school district that Colby attended for the majority of his school years gave her an insider's glimpse into the intricacies of how the special education system works in public schools. As such, she understands that school and community inclusion are necessary for her son's growth and success in life. Alice Patton's experiences parallel Lisa's and Colby's experiences. For Alice, she found comfort in knowing Russ was so well-loved at school and in the community.

You know, just going out in the community, you know, it was like... 10 years ago, I would have been nervous about that, but because he's been in the district for so long, and he knows all of the aides, and everybody knows him, and they all know his quirks, and what he does, and you know, it's, it's comfortable knowing that he's safe and that [they] know him as well as we know him.

This form of support is exactly what parents of students with disabilities need and desire for not only their child's quality of life but the whole family as well.

When the family feels secure with how well people know and support their child they are more likely to trust the IEP team to help make the best decisions for their child during times of transition. For example, when creating goals for a student surrounding the transition to adulthood, teams write goals that are inclusively formatted for a student to succeed in the "real world." When asked how the IEP team was meeting the needs of his son through inclusive practices in the school and community setting during transition, Mr. Grier stated, "It was easy to

kind of dovetail those into goals.” This seamless application of using goals to build a comprehensive program for Matthew’s schooling and transition made the collaboration and planning with the IEP/ITP team a positive experience for the family.

Academic inclusion was not as common in American public schools for the participants and children during the time of the students’ early academic years. Many schools and districts were attempting inclusion realizing that it benefits all families and students. While inclusion is recognized as best practice, the implementation and organization of inclusion programming proved difficult as this new concept in education unfolded over time. Older generations of teachers were not necessarily prepared to teach students with special needs, and the idea was not readily discussed during IEP meetings over 15 years ago. Julie, Eric’s mother, said she would have eagerly accepted an opportunity for Eric to be in general education full time. When asked if she would have placed Eric in general education she stated, “Yes, if it had ever even been brought up as an option to me. I don't even know if it's just not brought up as an option, or if it is now and it just wasn't 15 years ago.” Julie believes that all children should be offered the chance to be included in the general education classroom saying, “Yeah, I definitely think that that should always be offered as an option to kids.” The fact that inclusion was not brought up by the IEP team for her son until late in high school meant that he lost out on opportunities, both academically and socially, to associate with general education peers and their families.

With transition plans only being required for IEP programs within the United States for the past few decades, the students and their families in this study were some of the frontrunners in incorporating post-secondary goals into IEP development. Ideally, ITP goals are academically and socially inclusive with a majority of goals attached to transition plans revolving around attending local community colleges, trade schools, and work locations familiar

to the student. Inclusive transition programs built by IEP teams through comprehensive and inclusive goal creation ease familial concerns as they transition their child to adulthood; as a result, trust and positivity are perceived by parents as the team prepares their child for the transitions.

Personal Development, Self-Determination, and Emotional Well-Being for Coping Through Transitions. Emotional well-being is one indicator of a quality of life through transitions. Coupled with personal development and activities surrounding growth, emotional well-being was found to be directly connected to perceptions of IEP teams as supportive or unsupportive. Tracy, the mother of Maddy, shared how being an easy-going person with personal growth woven into her life has lessened feelings of anxiety and negative emotions surrounding IEP teams and support providers.

It's like she's obviously the way she is because of mom and dad. So, she's [Maddy] going to be easygoing, mom and dad are probably going to be easygoing. So that's how I feel like everybody's been great [on the IEP teams].

I have a degree in graphic design, and I was working full time. So now my goals have adjusted in the sense that now I do my graphic design work for the nonprofit that I'm involved in, which is for Down syndrome and Rady's children. So I kind of adjusted it so I still use my talents, but I use them in a different way. I don't use it to get paid. I use it for the good of people with Down syndrome and stuff like that, raising money and all that stuff. So the goal has changed in that sense.

Through adjusting her personal development to match her life as a mother of a child with Down's syndrome, Tracy has opened feelings of accomplishment and success within herself. She speaks proudly of her accomplishments despite having many obstacles that could have stopped her along the way. Maddy's last two years of high school, as she was approaching the transition to adulthood, were emotionally difficult for the entire family. Her brother was going off to college, she suffered a stroke her junior year of high school, and two of her grandparents

passed away all within the last two years of her K-12 school experience. These challenging years guided the family toward leaning on each other for emotional strength and development. At the same time, the family's positive perception of the IEP team was boosted when school employees rallied to assist Maddy and the entire family.

Having Maddy had a few hospital stays, it's always been nice to be able to say, "Hey, this is what's going on." And then the IEP team would be going to, "Okay, great. We're going to change this this way to make this better and stuff like that." So it's always been nice.

When times were emotionally tough and flourishing was not happening in the family's lives, they found solace within the school community and felt supported by the IEP team. This emotional uplift foreshadowed the transition to adulthood for Maddy and her family bolstering their positive perceptions of IEP teams.

I think they were sensitive to the emotion of, "Oh, my goodness. She's moving up and moving on." So I think it was just good that they would always be reassuring. It's going to be fine. It's going to be great, and it's going to be better. And that was always the situation. So that was always nice.

Coupled with personal growth and development within their family unit, these perceived empathetic actions gave the family emotional stability as a coping resource through their daughter's transition to adulthood. Rapport and trust of team members allowed a smoother transition for Maddy.

Eric's mother and family have always found a way to create typical experiences for him regardless of their life circumstances. Eric has down syndrome with cognitive delays and is the only child in his family of eight who has a disability. Julie, Eric's mother, always felt that she could get her needs met for a consistently satisfying quality of life for the whole family.

I honestly think you can do whatever you want to do regardless of your circumstances. So even though I have Eric and sometimes that might make something a little bit harder, if I really wanted to do something, we would get it done. Might take a little bit longer, it might take whatever.

Individually and collectively, the family decided to be inclusive of Eric even with the challenges of his disability. They have consistently adapted their lives to meet his needs while also enjoying a plentifully positive quality of life for themselves. As a result of continuing life as a “typical” family might create for themselves, Eric is considered to be socially adept, and he is eager to participate in activities that are similar to or with his typical peers. He also found independence in navigating areas of the school and community during his time in high school.

Julie described her initial anxieties about allowing Eric such independence:

When he was on the wrestling team, and he could walk to wrestling by himself and get there, first, I was so scared. Coach did not understand how scared I was. I'd be like, "Oh my God, is he there? Is he there? I'd go to pick him up at 5:00 and I'd be like, "Oh my God, I just hope he got there and he's where he's supposed to be."

Although emotionally difficult at the time, Julie found her way through her feelings and anxieties at the time to ensure a better quality of life for the entire family. She knew that the greater Eric's independence was, the more they could continue living a fulfilling quality of life. Julie grew as an advocate for her son and having the support of people on Eric's IEP team, like the wrestling coach, made the transitions approaching adulthood a more positive experience for the entire team. The strategies and supports Julie chose to access and use meant that the transition for Eric was virtually seamless in her eyes.

Young adults with disabilities often feel apprehensive about transitions, impacting those around them with their anxiousness. This time of apprehension is when parents might lean in more to gain support from the team and access strategies for coping through the transition. For Marta, the mother of Alfredo who is severely impacted by autism, emotional comfort easing anxiety came from the fact that the IEP/ITP team members really knew her son and what was best for him.

They always have a reasoning and they always had, had Alfredo's potential in mind. And that's what she saw that like, the, the best way that she felt supported was at, when the teachers explained his potential and the why of whatever things were going on, and that they would always have time to explain everything to her, like, "This is the way we're gonna work things out. This is the way we're gonna do it." And she always felt like she was in the loop and that's what she appreciated the most.

Team members' abilities to provide reasoning for certain goals and processes through IEP meetings and Alfredo's plan enabled Marta to feel more comfortable with each portion of her son's educational journey. Marta's willingness to trust and understand the team members' ideas and reasons made the transition to the district adult transition program smooth for this family. Alfredo is now thriving in the adult transition program. His family feels he is safe and growing, making IEP/ITP meetings positive in this case. English is Marta's second language, making the task of comprehending the steps in creating IEPs and ITPs more laborious; however, with the help of a translator and the support of the IEP team, Marta has developed her own knowledge of the special education systems in the public school system. Her growth and learning have benefited this family, resulting in more positive perceptions of the IEP teams.

Other families worried alongside their children as they went through certain transitions. For example, Christy Moreo, the mother of Ryan who is significantly impacted by autism, felt the difficulties of transitioning her oldest son to middle school from elementary school. She knew that he was worried about middle school and how he might feel there. She stated, "Then he obviously worried about the transition to middle school, which was completely anticlimactic and he loved middle school the whole time he was there." As her first of a major transition of matriculation into secondary schooling for her sons, Christy was able to personally maintain a positive attitude through self-determination in the transition. This emotional stability eased any

discomfort for Ryan as he entered middle school after being held back by his parents in elementary school for a year.

Christy kept this positive mindset as Ryan went through the transition to high school and then to the adult transition program. Ryan's mother is appreciative of the support and now that Ryan is full-time in the adult transition program, Christy expressed, "Well, I mean, I feel like Ryan's really, really, really, really happy with where he is." Her face lit up as she described how happy her son is in the adult transition program this year. Satisfaction with the IEP team and his placement has left time for Christy to tend to her other sons as well. The overall quality of life for this family has increased with Christy's self-determination and ability to trust the support of Ryan's IEP team.

A family's willingness to access supports and strategies through their child's IEP/ITP team, and personal development including intrapsychic work to provide emotional stability, increases the possibility of a seamless transition from high school to adulthood for these families. Conversely, some families feel that the dynamics of a familial quality of life fall back onto the family themselves. Mr. Grier, the father of Matthew who is high-functioning in basic social skills but very impacted by his anxiety stemming from his autism diagnosis, feels as though families should be more self-reliant. When asked how he perceives IEP team support in terms of the family quality of life domains, he stated:

Yeah. It, it's just a personal thing. It's like, I don't, I don't drive up and get bags full of food from food service. There's nothing wrong with the food. It's perfectly available. And it's all there and it's all free and they stream in droves. But no, I, you know, I, I live my life and we make enough money to, to live reasonable. So why would I do that?

Mr. Grier perceives an IEP/ITP team as solely related to his son's academic and life skills performance. He has chosen not to access certain portions of the team's offerings. "I don't look

to school for them” was his response when asked about family and their emotional well-being. With little support being accessed by the Grier family during Matthew’s transition, there were some unexpected hurdles that impacted the entire family. High school was not Matthew’s favorite time of schooling, as Mr. Grier stated, “He craves communication and feeling like he’s part of something. And in high school that’s impossible. Because every kid’s got their own agenda and their own ideas...”. Then, the pandemic occurred during Matthew’s senior year, and the Grier’s changed paths completely during his transition to the public school transition program.

And I was more than willing to start going to classes with him at [a community college], you know. But in some aspects online school has been good for him. You know, it’s not like he can do it completely on his own.

My wife has to sit through it with him. But every, every week, he, he goes a little further, just one more small step further, very small in facilitating for himself.

The COVID-19 pandemic directly impacted the dynamics in this family. Had they sought out further support within the school district, they may have had a smoother transition despite the novelty of the time period.

Emotional well-being, an indicator of quality of life, is tied to personal development and a family member’s ability to engage in intrapsychic and metacognitive practices. Families who chose to access or allow IEP/ITP teams to emotionally support them were more likely to impart on perceived seamless transitions with their children. The transition from secondary to postsecondary education can be draining for the family members involved with the student. Supports and strategies provided by IEP/ITP teams and used by families result in positive perceptions from the family members.

Perceived Barriers to a Supportive IEP Team

Barriers to perceiving an IEP/ITP team as supportive and trustful are common; however, as many participants explained, these barriers are simple to remove when the team is aware and onboard to ensure a seamless transition for the student. Communication is at the core of every working relationship within an IEP/ITP team. Other mitigating circumstances to a seamless transition involve IEP member actions and inactions, prior broken trust, and inhibition of action based on perceptions of self. These perceived barriers to a supportive and trustful team can lead to familial perceptions of tough transitions resulting in a lower familial quality of life through a major life-course transition. Barriers are avoidable when IEP/ITP teams use research-based frameworks of supports and strategies as guidance for the transitions to adulthood for students with significant disabilities and their families.

Interpersonal Relationships for Family Quality of Life Transition Planning.

Families who did not perceive themselves as “gatekeepers” for access to strategies and supports reported that the IEP teams did not necessarily offer detailed descriptions of programs, coping resources, or other options to create a seamless life-course transition. Conversely, parents were not always willing to access opportunities offered to them by IEP team members.

“Overpromising” certain options that were never followed through by either parents or other members of the IEP teams, resulted in more tumultuous times during transitions for these families. Strong, professional interpersonal relationships within an IEP/ITP team lead to increased communication between teams and families. Some families struggled with focusing on a positive sense of self or lacked knowledge of how to increase self-determination resulting in more frustrating transitions. As a result, strong interpersonal relationships amongst IEP/ITP team members were not formed, and planning for the future of the students was perceived as arduous and unhelpful for some families.

Perceptions of familial self and self-determination influenced how family members viewed their interpersonal dynamics within IEP teams, like Andrea, mother of Oscar, described:

And it's like, I'm not the type of person to be so nosy. And I guess in a way, I think maybe I have to be, but when you don't have other people that know how the system works around you, then you are just going through the motions. And that's, I think, another thing because of the IEP. Yeah. It would've been great, if someone would've told us, you know what? You have to go here. Maybe you need to ask for this, talk to this person. Or I know this person, I'll try to see if I can set up a meeting, but for there always to be a constant communication. It's great at the moment, but what's going to happen month, a year from now. Everything kept changing every year, because we had to go through all these transitions.

Andrea went on to describe how she did not understand what was next for Oscar after high school. She assumed he would be attending a community college, but continued to question the end goal of the transition program due to the misunderstandings. IEP team members did not necessarily follow through with their action items from the IEP meetings. Andrea said that there were a couple of teachers in high school that assured her they would help her with the process of admission to the regional center for Oscar, as well as provide other information regarding the process of conservatorship. Unfortunately, action items were not always followed through on, leaving Andrea to navigate the processes on her own; however, it should be noted that she admits not following through on her portion of the support resources.

The inhibition of action within the IEP team, including family members and support providers, resulted in Andrea not accessing the coping strategies and resources for her family during Oscar's transition to adulthood. In this case, a lack of a strong sense of self, self-determination, and follow-through within the IEP team were detrimental to timely support for an improved quality of life for this family as her son transitioned to adulthood and the adult transition program. Andrea acknowledges that Oscar is now flourishing in the adult transition program, and she has become more self-aware increasing her collaboration with IEP teams. She

now understands that the IEP team members need to know her family and life to plan for her son. In her family's case, the lack of cultural proficiency on the part of IEP team members outside of Andrea's family's background made accessing, or even understanding how to access, supports from the IEP team difficult for both parties.

Andrea's story was not unique to the transition experience and how IEP/ITP teams can misunderstand a student from a different cultural background. A discrepancy between family experiences and action taken by IEP team members is apparent based on culture and language barriers. Similarly, the only other Latino family in this study felt as though the team was not able to understand their family's culture to create a cohesive plan early in high school for their child with a moderate to severe disability.

The Lopez family faced similar barriers to accessing available supports and strategies for their familial quality of life during Alfredo's school years; however, their experiences through Alfredo's transition to adulthood based on the actions of the teacher and IEP team members turned out to be a positive change in their perceptions of IEP teams. Before Alfredo's junior year, the Lopez family felt as though the language barrier made it difficult to garner a complete picture of Alfredo's education plan and day-to-day progress. When the team began reaching out to Alfredo's sister more frequently and utilized technological translation applications for communication, Mr. and Mrs. Lopez became more empowered and confident in being able to participate in IEP/ITP meetings and understand Alfredo's education. Alfredo's sister, Eva, also played an integral role in connecting her parents to the IEP team:

And there's like these loops, previously. She's, like, not saying that then, that they did not have, that Alfredo wasn't making strides, or the teachers weren't doing what they were supposed to. It's just that, at the end of the day, it was just so more instantly now, thanks to technology, thanks to communication. And, (laughs) and one thing she attributes is that, like she has me as a translator now, so I can translate things, I can be an open ... I can be a vault to communication. ...I can

actually communicate with the teachers and translate that to her and always, like if something goes on at school, they can contact me and then I can contact mom in Spanish. And she feels like there's always a constant communication and collaboration.

Ultimately, the Lopez's experience was positively impacted when the IEP/ITP team members and service providers accessed their own strategies for engaging the family; self-determination within the family unit and a willingness to continue trusting the school teams meant that resources were accessed and utilized by the Lopez family. Relationships within the team were fostered and the Lopez family felt comfortable enough to access school-provided resources. Employing the use of resources connecting school teams to a family's dynamic, native culture and language created a positive transition experience for the Lopez family.

Inaction or inhibition of action from IEP team members contributes to the deterioration of perceptions of support by parents. Trust takes time to establish between school professionals and families when there are consistently new service providers and team members. Mrs. Ferguson felt the fluctuation of staff members each school year, which made it difficult for her to establish trusting relationships within Sasha's IEP/ITP team. The rotating staff providing services for Sasha, coupled with action items not completed by IEP team members, imposed a distrust within Mrs. Ferguson. This inkling of distrust Mrs. Ferguson felt was enough to influence the family's quality of life during Sasha's years in high school and through the transition to adulthood. When discussing Sasha's teachers and service providers from that time, Mrs. Ferguson became a bit anxious and uneasy recalling the experiences.

I was very, not worried because ... I mean, what's the worst that can happen? Probably nothing too bad. But at the same time, I was very, not impressed, (laughs) not impressed. So yeah, that person quit within a couple of weeks and then they hired another person who was just a big personality with maybe not a lot of action to put behind it.

She described the teacher as, “a little strange,” and explained that at first, they were bumping heads regarding Sasha’s program in high school. Mrs. Ferguson said that this teacher was not following through with items discussed during IEPs. It was a difficult time for all of the Ferguson family.

...it was very rough for us. And also Sasha was having ... a rough, like emotional or behavioral time during that time as well when we started in high school. So it was just a rough time all the way around.

When she resigned herself to this teacher having certain strengths that could benefit Sasha during her junior year of high school, the Ferguson’s experienced a better quality of life all around. She shared how she coped during this time. “I just resigned myself to that's not what I was going to get out of her. And then I realized that she had other things to offer and, and it was fine.”

Empowering families to access strategies and supports, both internally and externally, increases positive perceptions of IEP/ITP teams during transitions. Family members may not always have the knowledge to ask the proper questions or even begin to understand the transition process. Accommodating families by meeting them where they are in their knowledge, lack of knowledge, or their preferred identity and cultural background fortifies IEP/ITP teams’ abilities to increase the families’ quality of life during times of transition. Building and fostering positive interpersonal relationships between families and school team members is essential to meeting family quality of life indicators in transition.

Collaborative Communication for Family Quality of Life Transition Planning.

Communication and collaboration are perceived barriers to families viewing IEP teams as supportive during the life-course transition of their children with disabilities to adulthood; they are also the most important component of building quality education and transition plans with a team. Communication and collaboration between IEP team members and families proved to be a

large portion of perceived barriers for different reasons. Miscommunications, lack of collaborative communication, and cultural misunderstandings interrupted the potential for a seamless and comfortable transition experience. Families who perceived their child's case manager and teacher as sufficiently collaborative and in constant communication were more satisfied with the transition experience and its impacts on their family's quality of life.

When a family feels that there was not enough collaboration prior to the IEP/ITP meeting they are more likely to have a negative perception of the IEPs and team members. As Christy learned through the years of having three sons with autism and in special education, teams are not always collaborative or welcoming in nature. Since she is adept in special education practices she understands the strategies needed to produce quality IEPs with team members. She stated that teams should be working toward collaboration before the IEP/ITP meeting.

Send me the draft IEP in advance. You should just do that automatically, then everybody comes to the table prepared. Because a lot of times, I see that, especially with people that like newer IEPs, they're nervous, they don't know what they're doing, and you sit there and there's a whole table people on the other side and you're just a parent and you're like, they've all read the reports, they all know what they're talking about, they've all talked to each other, and you're just like, "Okay, it's them against me. I hope it works out."

Simply providing Christy with the IEP paperwork before any IEP/ITP meeting would have alleviated the negative feeling of, "...it's them against me." Families have better IEP meetings and transitions when teams are prepared and ready to collaborate during meetings. Ryan's IEP team did not make the effort to collaborate with Christy. Not only did Christy feel unsupported, but she also was not able to access certain supports and strategies due to the broken rapport within the team.

Many times parents do not feel like they have spoken up enough in meetings in years past. Fear of the unknown, misinterpretations, and simply not knowing the IEP/ITP processes in

the early years of their children's schooling all played a role in parents' hesitancy to speak up and collaborate with IEP team members. For example, Maddy's mom, Tracy, would have changed aspects of Maddy's program if she could go back in time.

And I didn't have the support. I didn't have the friend, or mom circle like I do now, who would be more like, "You need to do this, you need to push for it, and all that." I didn't have that back then where I do now. So if I could take what I have now and go back, I would do it differently. But like I said, I wouldn't say it's not disappointing or not.

Tracy's inability to speak up during IEP meetings hindered her ability to access supports and strategies from IEP team members. The same could be true of her social well-being through Maddy's transitions in special education. Due to a lack of friendships and social supports, Tracy was unable to garner information that could have helped her better understand the IEP/ITP process. Collaboration crosses all environments in the world of special education, including informal conversations before and after school with other families. Tracy's apprehension in Maddy's early years impacted her actions toward building the strongest possible program for her daughter, even though it worked out for them through her transition to a new program. Lack of communication between all parties and across environments made transitions more difficult for the Simmons family. An increase in collaborative communication with Tracy, Maddy, and her family would have provided more opportunities for access to supports and strategies.

Mrs. Ferguson, Sasha's mother, felt that the communication with the classroom teacher/case manager for her daughter was not sufficient for feeling secure with the IEP/ITP team. Unfortunately, Mrs. Ferguson often had a difficult time communicating with one particular teacher during Sasha's high school years.

I think it really just boils down to communication. There was no ... You know, I don't, like I said, Sasha is pretty low on the abilities list and I, I have accepted that and I just want her to be happy and, and well cared for, is really my goals. And, um, so it didn't really matter a whole bunch to me what they were doing in the

classroom as long as Sasha was involved in whatever it was and having fun. Um, so I think it was just more a matter of communication.

Mrs. Ferguson wants nothing but the best for her daughter but admits that she has not always been receptive, especially as the years went by with Sasha in special education. When asked about actions and behaviors in IEP/ITP meetings that make the process more uncomfortable or less productive for the team, she stated, “I will take most of that, a lot of that on myself. I just feel like I became a little jaded as they went on because it just seemed to be, you know, presented for them more than me.” Communication was not happening between Sasha’s teacher, service providers, and her mother, and this took a toll on the Ferguson’s quality of life through transitions. “Um, I mean, it’s been mostly good... transition to adulthood. That particular case manager [for high school] was very new and young. So I had a lot of friction with her...” This friction was during a time in the Fergusons’ lives when support and strategies should be accessed and utilized for a comfortable transition. The school district’s adult transition program has been a better experience for the whole family. When discussing the assimilated transition, Mrs. Ferguson said, “The transition to ATP was, it was a breath of fresh air and it’s been, it’s been great the whole time. No complaints.” While the program has proven to be supportive for the family, the periods approaching, and then coping, during the transition were disrupted with negative feelings caused by a lack of communication and misunderstanding from IEP team members.

In sum, communication and collaboration are precursors to seamless life-course transitions for families who have a child with moderate to severe disabilities. The early years in special education are formative and foreshadow the impending transition year to adulthood. Impeding dynamics such as broken trust with prior IEP/ITP teams make it harder for families to be the initiators of communicative collaboration. The onus of trust and relationship-building

within IEP teams should be reciprocal in nature, but it should also be easier for team members who are not experiencing the life-course transition. Working together as an IEP/ITP team through consistent and clear communication is integral to building a supportive transition team.

Rights, Well-Being, and Broken Trust in Family Perceptions of School Team

Support. Families can take several years to “bounce back” from broken trust within an IEP team. Anxiety, stress, and negatively impacting emotions can surround IEP teams and meetings once families have what they perceive to be an unsupportive or inadequate IEP team. The emotions that a family feels through the transition of their child with disabilities to adulthood range broadly and the impact on the family is often felt by all members of the family. Families often face a declination in meeting quality of life indicators when trust is broken; in response, families could feel that teams are not supporting the rights of the family. At the beginning of Colby’s years in the public school system as a student severely impacted by autism spectrum disorder, Lisa Gershin felt like her son was not getting the services he needed in the school setting. Lisa considered hiring an advocate for Colby after speaking with her family member who works in the field of special education and provided support early in Colby’s school years. In discussing friction during IEP meetings she shared how difficult it was but how she found ways to cope and seek support.

Yeah, it was... And you know what? Uh, I was a little different, because I had a brother-in-law who was the Director of Special Ed in Los Angeles in one of the districts, so, he would tell me whatever I needed to know, and be like, "Okay, now, this. No, they're not going to tell you this information because school districts don't want to willingly give away their money and their stuff," and he goes, "I'm... I know that because I'm here," and he's all, "It stinks, but this is just, you know, because we're all fighting for money for programs, and we don't want to just willingly say, 'Oh, you can do this, or you can do that..."

The lack of outreach in programming for Colby by the IEP team impacted the family negatively early on in school. The family felt a sense of broken trust and sought outside resources to cope with the intense emotion surrounding IEP/ITP meetings, including hiring an advocate.

...you know, [I] was involved, but until then I was like I, I don't know what I'm doing and I don't know who to call or who to ask, and that's why it was like the school district isn't going to just volunteer stuff to you. You have to get it on your own, so that was one downer that I would say with the school district. I mean, I understand. I work in the school district now, so I know why, but as a parent it was.

We had our ups and downs. There were some times where I didn't like what we were doing on the IEP, but I was vocal about it and had to get an advocate and do all that kind of stuff. But the school was still cool. They weren't like, "I hate you for making us jump through hoops to get your son doing whatever, whatever."

Uncertainty as a new parent with a child in public schools, added with a reluctance by the IEP team to provide better support, left the Gershin family untrusting of the IEP/ITP teams. In hiring an advocate for Colby, the family was able to receive an iPad for assisted communication in his learning environment. Broken trust meant that the Gershin's sought their support through an advocate. After having the advocate for a couple of years, Lisa felt more prepared to be her son's advocate during meetings and she moved away from using the paid advocate during meetings. Although the advocate only assisted during Colby's elementary school years, middle and high school went smoothly with just a few bumps in the road since Lisa previously experienced distrust in an IEP team.

Trust takes time and commitment from all members of an IEP/ITP team which proves difficult when the field of special education has an exorbitant amount of teacher and service provider burnout and turnover rates. Committing to too many areas for teachers and service providers often leads to inaction by team members. Overcommitment with unfulfilled promises impacts not only the team but the student and the family's quality of life. Mr. Grier experienced

this as his son, Matthew, was approaching and commencing the transition to adulthood. One of his high school teachers wholeheartedly desired to provide more for Matthew's program, but this teacher fell ill and was not working full-time. These action items were never tended to or delegated to another service provider, and as a result, trust was broken and the family suffered, as Mr. Grier describes:

And then [his teacher] of course getting sick and then it all kinda went to shit because he was, he really bought in...

God bless him. Every once in a while he pops up, sends an email, "Hey, how you guys doing? I wanna take you out for lunch." It's always I wanna take you out for lunch. And then I send an email back and I get crickets (laughs).

I'm sure everybody else deals with the same thing with him (laughs). So, you know, Matthew has learned, don't, you know, don't count on that. When it comes, it's nice. It's a bonus. But, you know, he'll send a text to somebody and he'll stand there, he'll just stand there looking at the phone waiting for something to come back. It really doesn't quite work that way these days.

I can kind of read a lot of body language. And Matthew actually, believe it or not, has some good skills in that regard too. He does. ... That's why he doesn't trust people.

Extenuating circumstances of having a teacher in and out of the classroom due to health issues does not necessarily fall on that teacher; however, the IEP/ITP team did not sufficiently take over for Matthew's teacher resulting in emotional turmoil within the family unit and a newfound distrust altering perceptions of IEP teams as trustful professionals.

Communication prior to transition experiences, as well as through the assimilation of the transition by the family, is necessary for parents to feel supported by school teams. Julie's experience with Eric matriculating to the district's adult transition program was negatively influenced based on uncertain protocols and practices during the COVID-19 pandemic. Before the pandemic, students in the adult transition program would go out in the community daily for community-based instruction. Mandates and regulations created to ensure public safety during

the pandemic limited the adult transition program experience for Eric. During his second year in the adult transition program, Eric had many more opportunities to explore his community, work experiences, and social gatherings.

I'll be like, "Are you sure you're doing this?" And he's like, "Oh no. No, I don't know. And so, I just feel like I need a little bit more of that. ... And I trust everybody. But getting used to that first... Because to me I feel like this is our first full year, because we only were there a little bit last year and everything was off. They didn't do the community stuff like they're doing this year, and all that kind of stuff. So, for me, this is like our first year and I just needed a little bit more communication on things.

The uncertainty of programming in public sector special education systems meant students had varied and different experiences from year to year. Distrust was felt in families and teams from this shift into a novel and unknown setting, regardless of positionality in IEP teams. When the school year started again for Eric, in-person learning began for his program. This shift to full-time attendance at the adult transition program meant Julie was seeing Eric move through his days in a more engaging program. The dearth of applicable and accessible community activities during the pandemic left the family believing the adult transition program was not as robust as it turned out to be for Eric. Had Julie received more communication regarding the programming of adult transition students before and during the pandemic, she most likely would have felt at ease with the busyness of a typical adult transition school year. Retrospectively, Julie felt a distrust that meant her own emotional well-being was threatened as her son was going through a life-course transition.

Trusting relationships in IEP teams can promote or obstruct a family's ability to perceive the transition to adulthood for their child as a positive experience for the whole family. These moments in time during transition set the tone for a family's quality of life in almost all areas; specifically, the emotional well-being of the family members at the time of transition can be

swayed by the support (or lack of support) of school professionals. Supports, strategies, and actions within the systems are held by school IEP team members who have the resources to assist families in transition with their children. Ensuring the family knows their rights and building trust within IEP teams is paramount for the overall well-being of families going through transitions.

Conclusion

This chapter reported the findings from an analysis of interview data gathered with parents/family members of nine young adults with moderate to severe disabilities who have undergone the transition into adulthood with a supporting IEP/ITP team. Their lived experiences highlight areas of strengths and weaknesses in how IEP/ITP teams and public systems support families for a positive quality of life as their children/family members transition into adulthood. Interwoven in each of these stories are complex interpersonal dynamics that impact the lens from which families view transitions in life. IEP/ITP team members have the ability to sway the lenses of family members either positively or negatively depending on how they provide support. Meeting a family where they are in all areas of their lives, while also mitigating personal and systemic barriers to building trusting relationships, will ensure teams are following practices that create a positive experience for families.

Chapter 5: Discussion and Conclusion

This final chapter begins with an overview of the study including the problem and purpose, research questions, and methodology. Following this overview is a summary of findings delineated by each research question in the context of previous research. Implications for utilization of this study in the domains of practice, policy, and the need for further research in the area of special education transitions involving the collaboration of families and IEP/ITP teams, follow the findings. Finally, there is a concluding section about the need for better practices in the area of special education transitions.

Overview of the Problem and Purpose

Parents and families of children with moderate to severe disabilities have many transitions throughout their children's lives. These transitions ultimately impact an entire family unit's quality of life at different stages and ages for their child with a disability. The purpose of this study was to describe and analyze the experiences and perceptions of parents who have children with moderate to severe disabilities as they go through the transition from high school to post-secondary programs and services. Nine parents of students with moderate to severe disabilities who are, or were, currently in a public adult transition program participated in in-depth interviews about their experiences of perceived support or lack of support from IEP teams and meetings throughout the transition process. The participants consisted of the parents and family members of nine young adult students attending (either currently or in the past three years) a San Diego County public school adult transition program, ages 17-24. Semi-structured interviews with follow-up member-checking emails were completed over the course of 8 months. The goal of the study was to provide parents of students with moderate to severe disabilities, who have engaged with IEP team members for many years, a voice regarding transition practices

for students matriculating from secondary to post-secondary education and life. Opportunity for expression of parents' perceptions and experiences with IEP/ITP teams segued to in-depth conversations surrounding how these teams impact families. Previous research shows that the whole family is impacted by a student with disabilities transitioning to post-secondary life (Scanlon et al., 2017; Gur et al., 2020). Team members' actions, behaviors, and plans directly influence a parent's perspective of how smoothly transition and IEP/ITP meetings occur for their child (Bakken & Obiakor, 2019).

Themes in the experiences of the families transitioning a child to post-secondary life were identified following the gathering and collecting of data. The research questions presented in this study were addressed and answered by the analysis of data and themes. Data gathered from this study adds to the research in the areas of IEP/ITP support in transition and family quality of life within special education systems. To reiterate, the study addressed the following research questions and subquestion:

1. How do parents of students with moderate to severe disabilities experience the transition of their child to post-secondary life when supported (or not supported) by public school IEP/ITP team members?
 - a. How are QOL domains and indicators being met (or not met) for students and families experiencing the transition to adulthood?
2. How do parents of students with moderate to severe disabilities perceive IEP teams prior to and during their child's exit from secondary schooling in the transition to adulthood?

The following is a summary of the findings in relation to each of these research questions. Prior research is woven into these findings as a reference.

Firstly, it was a goal to understand IEP/ITP transition meetings prior to entering adulthood. Parents' interpretations and formed conceptions of a team are what can often set the tone for a meeting. As parents described IEP and ITP meetings throughout the years of having their child in special education, the most prominent data showed parents' preconceptions of a team influence their perspectives on lived experiences of having a seamless or tumultuous IEP/ITP transition meeting before adulthood.

Findings for Question 1

The main research question of this study asks: "How do parents of students with moderate to severe disabilities experience the transition of their child to post-secondary life when supported by public school IEP/ITP team members?" The study revealed that families of children with moderate to severe disabilities are impacted by their children's transition to postsecondary education and life with IEP/ITP team meetings and experiences either helping or hindering a seamless transition for a better quality of life. This study also showed that parents can feel vulnerable and anxious regarding their child's conclusion of high school and entrance into adulthood corroborating a study of parents' perceptions of the years following high school for their children with disabilities (Bianco et al., 2009). These feelings often translate into more difficult IEP/ITP meetings during this time. Undoubtedly, the participants of this study were critically impacted in their transition experiences due to the global pandemic of COVID-19. These alterations to how public schools teach, plan, collaborate and work left families feeling uncertain and anxious about the future for their children and the world. During the pandemic, the dynamics and infrastructures of the education systems were temporarily changed to virtual and digital formats, shaping research results (Vindrola-Padros et al., 2020). Unprecedented techniques and systems were put into place and essentially became an entire social experiment,

in and of, themselves. The pandemic brought out both positive and negative components for families whose children were transitioning to adulthood and post-secondary education in a public special education program. Only one participant in the study had a child who had assimilated through the transition to adulthood, graduated from an adult transition program, and is currently attending an adult day program.

Prior research shows families' transition experiences are comparably smoother when the IEP/ITP teams provide families with supports and strategies for a better quality of life (Neece et al., 2009). Parents in this study were influenced by the supportive and unsupportive actions of IEP team members, which in turn, provided a lens for families to view transitions for their children as seamless or difficult. At times, coping strategies were used by parents who found a way to indulge in positive intrapsychic work. Intrapsychic work can change a person's abilities to willingly access coping strategies within or through external resources (Anderson et al., 2011). Some families were able to change their perception of transitions based on their personal development and self-initiated growth. In the case of Mr. Grier and his son, Matthew, their plans completely changed based on the shift to virtual learning during the pandemic. The Grier family had made plans for Matthew to have an in-person, customized program; when online learning began, the family shifted the path for Matthew to solely basing it around online community college versus accessing adult transition program academics. Matthew found great success using this platform for his first-year post-high school. After seeing Matthew's ability to adjust his life plans with contentment and success, Mr. Grier modified his thinking surrounding the transition to adulthood providing a positive lens for the entire family. Positive perceptions of self used as a coping resource based on Schlossberg's transition theory, along with the quality of life domain of self-determination within Schalock's quality of life framework, made the transition easier for

the Grier's, translating into smoother IEP meetings and experiences (Schlossberg, 1981; Schalock, 2000). A family's efforts to understand themselves, and each others' positive qualities, directly impact how they access strategies and supports provided by service providers. Ferrer et al. (2017) discovered that when members of a family possess ethos dwelling in positivity and hope, their experiences in having a family member with disabilities transition to a new life course will increase the quality of life for all.

Families take on uncomfortable emotionality during their child's transition to adulthood in anticipation of what comes next in life (Cheak-Zamora et al., 2015). Action toward mitigating negativity in the family dynamic can involve incorporating the child with disabilities into all realms of life through the use of supports (King et al., 2006). Lisa Gershin, the mother of Colby, ensured her son was integrated into her family's daily lives and activities. Integrating her identity as a mother of a son severely impacted by autism spectrum disorder on a daily basis empowered Lisa to be a strong advocate for Colby bolstering the family's quality of life during transitions. Empowerment and self-determination led to Lisa's inurement and gaining new knowledge to assist with the specificities for Colby's IEP/ITP. Families lacking specificity in their planning for the future with their child leads to generalized goals resulting in diminished success and quality of life for the whole family (Lee et al., 2019). Self-determination, such as the positive actions the Gershin family engaged in, creates a more seamless transition. Renegotiation of roles as a child transitions to adulthood within a family unit is easier when IEP/ITP teams foster self-determination for all members. Self-determination builds esteem within family members allowing for a lens of positive perception (Wehmeyer, 2014; Canha et al., 2012).

Positive perceptions utilized as coping strategies, even through times of stressful events like a transition, elicit greater contentment and overall family quality of life (Hastings & Taunt, 2002). Accessing and using coping strategies from internal or external sources crystallizes a member's ability to perceive themselves through the event of transition; purposeful action taken with specificity as a component of planning creates a positive trajectory for the student and the family. Pragmatically-informed transition plans, coupled with school teams appropriately providing access to supports and strategies for families, can lead to seamlessly supportive transitions for all stakeholders.

Findings for Question 2

The second research question asks: "How are the quality of life domains and indicators being met for students and families experiencing the transition to adulthood?" Often, families experiencing the transition of their child with disabilities to adulthood realize transitions are difficult based on responses from family members, their child experiencing the transition, and the child's IEP/ITP team (Wehman et al., 2017). Taking inventory of quality of life indicators and transition resources in congruence with IEP/ITP teams can help specify which supports are needed for areas of life where quality has declined for the family. Caregivers for a child with moderate to severe disabilities must negotiate public systems and attempt to access agencies and supports, all the while giving support to their child during transition times (Gauthier-Boudreault et al., 2017). Cognitive, psychological, and social/emotional delays in development mean that children with moderate to severe disabilities respond to change in vastly different ways (Blacher, 2001). Easing the stress of these impacts for families involves teams supporting families through communicative collaboration to assist in meeting quality of life goals (Ferrer et al., 2017).

Reciprocal relationships are necessary to mitigate feelings of exclusion and insensitivity in perceptions of teams by family members. Emotional well-being is one of the most discussed quality of life indicators in transition and special education; at times, social and academic inclusion were predictors of emotional well-being for families. In this study, Mrs. Ferguson experienced a disassociation of engagement in meetings after a lack of social inclusion. She believed that the meetings became solely about the process for the school, and service providers/team members, with little communication or collaboration about the specific needs for her daughter. This reduction in reciprocal power during meetings confirms findings from a previous study conducted by Lake and Billingsley (2000) showing that discrepancies and conflict within IEP teams follow a loss of perceived power. Christy Moreo experienced the same destruction of collaboration citing the teams' inability to provide an IEP/ITP draft in advance placing her in a position of feeling like it was her against the school providers. Feeling unprepared to collaborate during a meeting based on the inactions of IEP team members is easily avoidable with documents being provided to parents prior to communication and meetings (Mueller, 2017).

Community and culture (IEP teams, school, district, home) play an active role in the transition of a student with disabilities to adult programs and services (King et al., 2006). Inclusion of family members in the offerings provided within the varied contexts of their communities assists with an overall sense of belonging and well-being (Leonard et al., 2016). Inclusivity imparted emotional well-being and strength in interpersonal relations for Tracy, mother of Maddy, leading to deeper understandings of the transition process. Through the years, other parents of children in Maddy's classrooms have been sources of support, friendship, and knowledge for Tracy. Bianco et al. (2009) completed a study similar to this one and found

parents did not necessarily self-initiate support groups, but they did view other families of children with disabilities as mentors for ideas and decisions about their own child's programming. Similarly to this study, families found ways to cope with the transition for their children in the absence of formal supports offered by support providers.

One avenue of enabling an anxiety-free transition is through personal development and making adjustments to the conceptualized ideas of their child's education program. Families who have faced discrepancies regarding their child's program are less apt to access forms of support being offered by support providers (Lee et al., 2019). When Lisa hired an advocate, modified her own thinking about Colby's course through school, and accepted his path in functional skills, she boosted her own emotional well-being for active participation in IEP/ITP planning. Feeling emotionally stable and engaged during times of change promotes clarity to intricately plan transitions for a child (Mueller, 2017). Colby's parents and siblings communicated with each other about the future as a family, with Colby's needs always being inclusively woven into their family plans. Input from all family members, as they experience varying levels in their perceptions about quality of life, is important for a transition plan to be executed successfully.

A study by Lee et al. (2019) showed that parents of a child with moderate to severe disabilities going through the transition to adulthood were stressed by demands put on the family and financial concerns; however, siblings were impacted more by the transition concerning social and interpersonal skills. Interestingly, there were more family-related barriers to a seamless transition than systemic and individual barriers. Lee et al. revealed how families experience transitions, collectively and individually, while experiencing differing opinions, thoughts, and levels of contentment in correlation to a quality of life. Nurturing communication

and involvement, between and with family members, imparts perceptions of familial support related to IEP/ITP team members. Families perceiving support from team members go through more seamless transitions than families who struggle to access and engage with each other and the IEP/ITP teams.

Findings for Question 3

The third research question asks: “How do parents perceive IEP team members prior to and through their child’s transition to adulthood?” Families of children with significant disabilities interact and collaborate with dozens and in some cases hundreds, of doctors, specialists, and different service providers for a chance at growth throughout life for their child. Collaborations made accessible to all stakeholders for transition should occur frequently and as needed to adjust to the needs of the child (Bakken & Obiakor, 2019).

It has long been noted in research that collaborative efforts and meaningful planning through consistent communication are best for fostering a trusting and supportive IEP/ITP team (Brotherson, et al., 1993; Wehman, 2014; Hsiao, 2017). This study, albeit, conducted during a pandemic, confirms these findings and illuminates the dearth in the progression toward better supports for families of students with moderate to severe disabilities going through the transition to adulthood. Perceptions of IEP team members begin early for many of these families with public education systems providing services to students as young as three-years-old. Families who continually have negative experiences with schools and professionals year after year are less likely to rely on the available school supports (Wong et al, 2020). Contrasting the goal of collaboration within IEP/ITP teams to support parents and confirming this concept, a study conducted in Australia in 2016 found parents of children with autism spectrum disorder transitioning to adulthood through public systems were less likely to consider school teams a

support for their family. Negative experiences, and more specifically, those experiences with teachers, led these families to feel distrust and dissociation with school personnel.

Another study from 2020 with 40 participants in 10 different focus groups explored the perspectives of parents whose children with autism spectrum disorder have gone through the transition to adulthood and concluded “...although transition planning and services are inherently cross-disciplinary and cross-organizational, in practice services tend to be segregated with poor integration, communication and collaboration across critical providers” (Snell-Rood, et al., 2020). Participants in this study described similar circumstances of having only certain team members giving support and solely relying on those specific team members; more specifically, all participants in this study found teachers/case managers to be of greatest influence in their children’s educational experiences. When asked about her son’s experiences in the public special education systems, Christy Moreo admittedly stated that she believes it is not necessarily the district, programming, or school culture impacting her son’s educational gains. She found that regardless of any other factors, it is the teachers/case managers who have positively impacted her son’s special education experiences and growth. Building trust in a team takes time; however, interpersonal relationships and dynamics between the family and teacher/case manager have a greater bearing on how the family perceives the IEP/ITP team’s support through transitions.

Parents may already have authentic views of IEP team members based on previous interactions prior to transition meetings; sageness benefits these families as they discern who are trustful and supportive providers on the team. Mr. Grier, the father of Matthew, dealt with blatant disinterest in collaborating for his son’s IEP when, on more than one occasion, he watched one particular administrator shop online for clothes during his son’s meetings. The

action taken by this school professional on Matthew's IEP/ITP team created reactionary distrust in the schools for the Grier family, which took time to resolve through the years. Distrust of IEP team members is not only caused by visible actions during meetings.

Inhibition of action by team members also has the potential to cause family members to reflect and lose trust in providers, as well as school supports and strategies. Cultural differences and misunderstandings have the potential to cause breakdowns in team efforts and abilities to offer support through transitions. Andrea experienced a lack of interagency collaboration, as well as team members who did not follow through on assisting the family in accessing adult services, which, ultimately, infringed on the trust she previously had in the school systems. Conversely, Marta and Eva Lopez felt a connection to Alfredo's education and team members during his last two years of high school once his teacher/case manager began relaying information and resources using translation and technology applications. The teacher became a crucial link in their seamless transition of Alfredo into adulthood. Integrating linguistically and culturally relevant supports offered by IEP teams assists in establishing positive rapport between families and team members.

Accessing coping strategies and resources requires families to be prepared for team collaborations such as an IEP/ITP meeting. When documents are not sent home before a meeting or options are not effectively communicated, families feel discontent with a lack of constructive collaboration for their children with moderate to severe disabilities. When teams do not provide options for post-school options and proper agency linkages, parents get lost in the process of transition and planning for it (Singer, 2002). IEP/ITP teams who are prepared and engaged in consistent communication when families are approaching, going through, and

assimilating the transition to adulthood for their child equip families for seamless, positive adjustments in their lives.

This study corroborates the few prior findings from previous studies involving school system supports and family quality of life during life-course transitions in special education (Ferrer et al., 2017; Hsiao et al., 2017; Boehm et al., 2015; Krishnasamy et al., 2016).

Participants in this study were uniquely impacted by their child's transition to adulthood due to a historical infiltration of a global pandemic and its restrictions. Families were uprooted from their normative practices of accessing supports and services for their children with moderate to severe disabilities. This new lens for projecting future plans meant family members were all going through their own transitions daily. The ever-changing, unfolding of pandemic events increased anxiety, stress, and feelings of uncertainty for families. Novel times resulted in a unique study of these nine families and their experiences in the special education system.

Tumultuous times exist in all circumstances of life at times; changes in life for children and their families elicit stress and responses from those impacted by the change. In this study, family members faced unmitigable, extenuating circumstances from the external source of the COVID-19 pandemic. While this added stress may have altered perceptions, the overall themes found surrounding transition in this study resonate with almost all families who have had children in special education during a typical year. If educators and public school systems are truly living missions of learning and support, then it is imperative to continue shedding light on inequitable resources by giving voice to families and students in special education.

Implications for Future Research

Further research in the area of IEP teams and transition experiences for families is needed for a better understanding of how each specific support parents are offered by a team meets the

unique, individualized, and specific needs of their family. Strategies and resources used for coping through the transition process should provide support based on specific needs; yet, research continues to show generic and prescribed supports are offered to families who are unwilling or unable to access them (Lord Nelson et al., 2004). Follow-up studies have the potential to illuminate how individualizing transition supports, and including specificity in transition plans, increases the positive impacts for familial quality of life through the transition to adulthood. Research involving the cross-reference of student IEPs/ITPs supports accessed by families, and familial quality of life indicators as perceived by family members would garner a broader view into how teams can be more individualized in supporting families during the transition to adulthood.

Systemic barriers to seamless transitions for familial quality of life in families with intersectionalities should be further explored in transition research. A lack of studies and literature involving special education transitions for a quality of life in families facing intersectionalities leaves teams underprepared to meet specific needs for transitioning a student whose family culture is different from school teams. DisCrit, the combination of disability studies and critical race theory, continues to gain traction in disability education research; refining these tenets to hone in on quality of life through adult transitions could assist in reforming practices for culturally and linguistically diverse families.

Implications for Practice

The findings of this study yield important implications for practice in special education transitions. These implications offer suggestions for improving transition practices in public special education systems to increase the quality of life for families transitioning their children with moderate to severe disabilities to adulthood. This research can contribute to the national,

state, district, and school-wide knowledge, policies, and practices for transitioning a special education student with significant disabilities to adulthood and/or an adult transition program. The implications provided are easily modifiable and adaptable to each family and their specific needs.

Recommendations for Service Providers, Schools, and Districts

The following suggestions are based on the findings from this study and can be used to supplement current practices in schools and districts. Minor alterations in how IEP/ITP teams meet families with supports, resources, and strategies, to bolster a seamless transition and positive quality of life for the families they support, will move forward equitable growth in services provided to students in special education. Below is a description of specific strategies to be used during transitions and IEP/ITP meetings to ensure parents perceive the team as supportive of their child and family to stoke an overall positive perception for a seamless transition.

- Cultural proficiency should be of importance to IEP/ITP members outside of the family, as they are often not from the same background as the students they serve. Training and professional development should be available for teachers and service providers working in special education. Transition-specific cultural training would fare best for serving families as they go through life-course changes.
- Readily available supports and information, such as a directory of services provided to parents that give families options for counseling, transition, and adult services, should be integrated into meetings and communication with families.

Offering these supports appropriately requires teams to understand the student, family, and culture in regards to their life plans.

- Awareness and understanding of the familial quality of life indicators and communication strategies, through the use of school- or system-provided inventories, frameworks, and guides would create stronger working dynamics within teams for families to access services and supports during transitions.

Adapting research-based inventories and frameworks to suit families being served in schools is a simple task requiring minimal effort while benefiting all of the members of IEP/ITP teams.

- Family involvement in the IEP/ITP planning process is the most important element of special education teams and meetings. Family involvement should be of utmost importance as a goal for districts, schools, and service providers. Encourage families to participate by (a) creating welcoming environments, (b) providing workshops and trainings on relevant transition and family topics, and (c) incorporating family ideas with specific components and actions into the transition plan for the student.

Public school systems with special education programs should recognize and plan for the transition to adulthood of all students with disabilities (Singer, 2002). Transition plans within IEPs are generally not outlined until a student is between the ages of 14 and 16; as a result, the onus of cultural sensitivity and unveiling the processes for transitioning a student into adulthood often lies on high school teachers and case managers (Singer, 2002). To relieve the pressure of hastily-created IEPs and ITPs, schools should begin the discussion of the transition into adulthood for students with moderate to severe disabilities as early as elementary school and no

later than a student's 14th birthday (Kohler et al., 2016). The suggestions provided are easily melded into current transition practices in public school systems and should be considered to benefit families of students with moderate to severe disabilities. In time, reviewing the integration of new support strategies outside of the current rigid protocols will shape research and practice in special education. Positive impacts from the use of new supportive strategies may cause constructive policy changes to benefit students and families in the public special education systems.

Recommendations for Families

The following recommendations are based on the narrative findings in this study and previous research surrounding familial quality of life through special education transitions. Engagement of these recommendations by families increases the likelihood of family members accessing and utilizing the available resources in public special education systems of support. Findings from this study show inhibition of change in thoughts and actions can stem from a reluctance and/or misunderstanding on the part of family members. To diminish these possible barriers, each family strategy provided below includes recommendations for team members on how to introduce the strategy/support to family members.

- Family members should gather for the purpose of gaining new knowledge and understandings about the transition process. Collaboration and communication within peer groups, as families who have children with disabilities, creates a system of support for these families as they navigate the processes of transitioning their children to adulthood (Mueller, 2017).
 - Teams can foster the manifestation of support groups between families by offering a space and time to come together without the pressures of service

providers and school professionals being in attendance. Having service provider team members available after group gatherings to answer any questions that arise from the support meeting would benefit families going through transitions.

- Family members, including extended family and siblings involved in a student's life, should be present at meetings and ready to offer input for the betterment of their loved one's transition plan to adulthood.
 - IEP/ITP teams can support involvement in IEP and transition meetings by preparing families with the proper knowledge and skillsets to plan for their child. Providing proposed goals, student progress on current goals, and information about transition planning and services to families before meetings will ensure a more productive planning time.
- Family members should seek time and space away from their children for personal development and social interactions. Seeking guidance as needed to learn about transitions and how to process through them will assist families in being prepared to create pragmatic ITPs.
 - Social events, volunteer opportunities, and solicited information can be perceived as supportive to family members and should be considered an opportunity for service providers to teach and help families. When families have a sense of support from school personnel they are more willing to collaborate for the success of their children.

Conclusion of the Study

By nature, the very act of transition is an organic and dynamic experience that is unique to each family who experiences it for themselves or loved ones. Special education prides itself on specific and individualized plans for each student with goals in federally-mandated areas of transition: post-secondary academics, post-secondary employment, and independent living. As such, supportive IEP teams are at the very core of ensuring each student with disabilities goes through life transitions with team agreed-upon goals in place leading them to purposeful and content lives in these domains. Empowering families by meeting them in a place of empathy and compassion, while providing resources and strategies through consistent and clear communication, is best in supporting families through these transitions. Imperatively, teams should make great efforts to collaborate with family members and understand the family culture to determine any barriers to a seamless transition, as well as to provide support to the family's quality of life. Professionals working in special education are often inundated with system protocols they must follow that can, at times, be perceived as discouraging and impersonal for families of special education students. In order to close the gap between special education transition theory and practice, specific and delineated supports and strategies promoting a positive quality of life for families should be implemented to ensure seamless transition experiences.

References

- Abriza, A., & Ahmad, R. (2017). Systemic barriers: the challenges in the provision of inclusive school libraries in Malaysia. *Malaysian Journal of Library & Information Science*, 15(2), 19-40.
- Anderson, M., Goodman, J., & Schlossberg, N.K. (2011). *Counseling adults in transition: Linking Schlossberg's theory with practice in a diverse world*. Springer Publishing Company.
- Annamma, S. A. (2016). *DisCrit: Disability studies and critical race theory in education*. Teachers College Press. New York: Teachers College, Columbia University.
- Ankeny, E. M., & Lehmann, J. P. (2011). Journey toward self-determination: Voices of students with disabilities who participated in a secondary transition program on a community college campus. *Remedial and Special Education*, 32(4), 279-289.
- Bakken, J. P., & Obiakor, F. E. (Eds.). (2019). *Special education transition services for students with disabilities*. Emerald Publishing Limited.
- Beck, S. J., & DeSutter, K. (2019). An examination of group facilitator challenges and problem-solving techniques during IEP team meetings. *Teacher Education and Special Education*.
- Bianco, M., Garrison-Wade, D. F., Tobin, R., & Lehmann, J. P. (2009). Parents' perceptions of postschool years for young adults with developmental disabilities. *Intellectual and Developmental Disabilities*, 47(3), 186-196.
- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106(2), 173-188.
- Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*, 120(5), 395-411.
- Brotherson, M. J., Berdine, W. H., & Sartini, V. (1993). Transition to adult services: Support for ongoing parent participation. *Remedial and Special Education*, 14(4), 44-51.
- Brown, J. (2016). Recurrent grief in mothering a child with an intellectual disability to adulthood: Grieving is the healing. *Child & Family Social Work*, 21(1), 113-122.
- Brunsting, N., Sreckovic, M., & Lane, K. (2014). Special education teacher burnout: A synthesis of research from 1979 to 2013. *Education & Treatment of Children*, 37(4), 681-711.
- Canha, L., Simões, C., Owens, L., & Matos, M. (2012). The importance of perceived

- quality-of-life and personal resources in transition from school to adult life. *Procedia-Social and Behavioral Sciences*, 69, 1881-1890.
- Cavendish, W., & Connor, D. (2018). Toward authentic IEPs and transition plans: Student, parent, and teacher perspectives. *Learning Disability Quarterly*, 41(1), 32-43.
- Cawthon, S. W., Caemmerer, J. M., & pepnet 2 Research and Evidence Synthesis Team. (2014). Parents' perspectives on transition and postsecondary outcomes for their children who are d/Deaf or hard of hearing. *American annals of the deaf*, 159(1), 7-21.
- Certo, N. J., Luecking, R. G., Murphy, S., Brown, L., Courey, S., & Belanger, D. (2008). Seamless transition and long-term support for individuals with severe intellectual disabilities. *Research and Practice for Persons with Severe Disabilities*, 33(3), 85-95.
- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). 'Transitions are scary for our kids, and they're scary for us': family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, 28(6), 548-560.
- Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage Publications.
- Davies, Michael D, & Beamish, Wendi. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on "life as an adjustment". *Journal of Intellectual & Developmental Disability*, 34(3), 248-257.
- Defur, S. H., Todd-Allen, M., & Getzel, E. E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Individuals*, 24(1), 19-36.
- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing Ethnographic Fieldnotes*. University of Chicago Press.
- Esquivel, S. L., Ryan, C. S., & Bonner, M. (2008). Involved parents' perceptions of their experiences in school-based team meetings. *Journal of Educational and Psychological Consultation*, 18(3), 234-258.
- Esterberg, K. G. (2002). *Qualitative methods in social research* (No. 300.18 E8).
- Ferrer, F., Vilaseca, R., & Guàrdia Olmos, J. (2017). Positive perceptions and perceived control in families with children with intellectual disabilities: Relationship to family quality of life. *Quality and Quantity*, 51(2), 903-918.
- Field, S. L., & Hoffman, A. S. (2012). Fostering self-determination through building productive relationships in the classroom. *Intervention in School and Clinic*, 48(1), 6-14.
- Fish, W. W. (2008). The IEP meeting: Perceptions of parents of students who receive special

- education services. *Preventing School Failure: Alternative Education for Children and Youth*, 53(1), 8-14.
- Francis, Grace L., Blue-Banning, Martha, Haines, Shana J., Turnbull, Ann P., & Gross, Judith M.S. (2016). Building "our school": parental perspectives for building trusting family-professional partnerships. *Preventing School Failure*, 60(4), 329-336.
- Francis, G. L., Gross, J. M., Turnbull, A. P., & Turnbull III, H. R. (2015). An exploratory investigation into family perspectives after the family employment awareness training. *Career Development and Transition for Exceptional Individuals*, 38(2), 68-77.
- Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing?. *Research in Developmental Disabilities*, 66, 16-26.
- Giangreco, M. F., Dennis, R., Cloninger, C., Edelman, S., & Schattman, R. (1993). "I've counted Jon": Transformational experiences of teachers educating students with disabilities. *Exceptional Children*, 59(4), 359-372.
- Gur, A., Amsalem, G., & Rimmerman, A. (2020). Parents' psychological, social and financial outcomes as related to the transition of their offspring with ID from adolescence to adulthood. *Research in Developmental Disabilities*, 105, 103740.
- Halpern, A. S. (1993). Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children*, 59(6), 486-498.
- Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: A paradigm shift for practice, policy, and research. *Child: Care, Health and Development*, 37(6), 806-814.
- Hartmann, E. S. (2016). Understanding the everyday practice of individualized education program team members. *Journal of Educational and Psychological Consultation*, 26(1), 1-24.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 49(6), 405-418.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American journal on mental retardation*, 107(2), 116-127.
- Henninger, N., & Taylor, J. (2014). Family perspectives on a successful transition to adulthood for individuals with disabilities. *Intellectual and Developmental Disabilities*, 52(2), 98-111.
- Hirano, K. A., Rowe, D., Lindstrom, L., & Chan, P. (2018). Systemic barriers to family

- involvement in transition planning for youth with disabilities: A qualitative metasynthesis. *Journal of Child and Family Studies*, 27(11), 3440-3456.
- Hirano, K. A., Garbacz, S. A., Shanley, L., & Rowe, D. A. (2016). Parent involvement in secondary special education and transition: An exploratory psychometric study. *Journal of Child and Family Studies*, 25(12), 3537-3553.
- Hirano, K. A., Shanley, L., Garbacz, S. A., Rowe, D. A., Lindstrom, L., & Leve, L. D. (2018). Validating a model of motivational factors influencing involvement for parents of transition-age youth with disabilities. *Remedial and Special Education*, 39(1), 15-26.
- Hsiao, Y. J., Higgins, K., Pierce, T., Whitby, P. J. S., & Tandy, R. D. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in Developmental Disabilities*, 70, 152-162.
- The Individuals with Disabilities Education Improvement Act, 20 U.S.C. §1401 *et seq.* (1990).
- The Individuals with Disabilities Education Improvement, 20 U.S.C. §1401 *et seq.* (2004).
- Janus, A. L. (2009). Disability and the transition to adulthood. *Social Forces*, 88(1), 99-120.
- Jones, J. L., & Gallus, K. L. (2016). Understanding deinstitutionalization: What families value and desire in the transition to community living. *Research and Practice for Persons with Severe Disabilities*, 41(2), 116-131.
- Jung, A. W. (2011). Individualized Education Programs (IEPs) and barriers for parents from culturally and linguistically diverse backgrounds. *Multicultural Education*, 19(3), 21-25.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education*, 47(2), 119-136.
- King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2006). The effectiveness of transition strategies for youth with disabilities. *Children's Health Care*, 35(2), 155-178.
- Kohler, P. D., Gothberg, J. E., Fowler, C., and Coyle, J. (2016). Taxonomy for transition programming 2.0: A model for planning, organizing, and evaluating transition education, services, and programs. Western Michigan University.
- Klein, S., & Schive, K. (2001). *You will dream new dreams: inspiring personal stories by parents of children with disabilities*. Kensington Books.
- Krishnasamy, M., Li, J., & Chen, D. (2016). Transition outcomes through the lens of quality of life: Proposing a consolidated framework. *Journal of Intellectual & Developmental Disability*, 41(4), 360-369.

- Lake, J. F., & Billingsley, B. S. (2000). An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education, 21*(4), 240–251.
- Landmark, L. J., Roberts, E. L., & Zhang, D. (2013). Educators' beliefs and practices about parent involvement in transition planning. *Career Development and Transition for Exceptional Individuals, 36*(2), 114-123.
- Lee, C. E., Burke, M. M., & Stelter, C. R. (2019). Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 57*(3), 198-211,259,261.
- Leonard, H., Foley, K. R., Pikora, T., Bourke, J., Wong, K., McPherson, L., Lennox, N., & Downs, J.(2016). Transition to adulthood for young people with intellectual disability: The experiences of their families. *European Child & Adolescent Psychiatry, 25*(12), 1369-1381.
- Lindsay, S., Duncanson, M., Niles-Campbell, N., McDougall, C., Diederichs, S., & Menna-Dack, D. (2018). Applying an ecological framework to understand transition pathways to postsecondary education for youth with physical disabilities. *Disability and Rehabilitation, 40*(3), 277-286.
- Lord Nelson, L. G., Summers, J. A., & Turnbull, A. P. (2004). Boundaries in family—professional relationships: Implications for special education. *Remedial and Special Education, 25*(3), 153-165.
- Martin, J. E., Van Dycke, J. L., Greene, B. A., Gardner, J. E., Christensen, W. R., Woods, L. L., & Lovett, D. L. (2006). Direct observation of teacher-directed IEP meetings: Establishing the need for student IEP meeting instruction. *Exceptional Children, 72*(2), 187-200.
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (Vol. 41). Sage Publications.
- McDonnell, J., & Hardman, M. L. (2009). *Successful transition programs: Pathways for students with intellectual and developmental disabilities*. Sage Publications.
- Miner, C. A., & Bates, P. E. (1997). The effect of person-centered planning activities on the IEP/transition planning process. *Education and Training in Mental Retardation and Developmental Disabilities, 32*(2), 105-112.
- Mlynaryk, C., Laberge, M., & Martin, M. (2017). School-to-work transition for youth with severe physical disabilities: Stakeholder perspectives. *Work, 58*(4), 427-438.
- Moustakas, C. (1994). *Phenomenological Research Methods*. Sage Publications.

- Mueller, T. G. (2017). Promoting collaborative partnerships with families. In *Handbook of special education* (pp. 773-792). Routledge.
- National Education Association of the United States & United States. (1978). *P.L. 94-142: Related federal legislation for handicapped children and implications for coordination*.
- Nowell, B. L., & Salem, D. A. (2007). The impact of special education mediation on parent-school relationships: Parents' perspective. *Remedial and Special Education*, 28(5), 304-315.
- O'Brien, G. (2006). Young adults with learning disabilities: A study of psychosocial functioning at transition to adult services. *Developmental Medicine and Child Neurology*, 48(3), 195-199.
- Papay, C., Unger, D. D., Williams-Diehm, K., & Mitchell, V. (2015). Begin with the end in mind: Infusing transition planning and instruction into elementary classrooms. *TEACHING Exceptional Children*, 47(6), 310-318.
- Plotner, A. J., Mazzotti, V. L., Rose, C. A., & Teasley, K. (2018). Perceptions of interagency collaboration: Relationships between secondary transition roles, communication, and collaboration. *Remedial and Special Education*.
- Prince, A. M., Katsiyannis, A., & Farmer, J. (2013). Postsecondary transition under IDEA 2004: A legal update. *Intervention in School and Clinic*, 48(5), 286-293.
- Rehfeldt, J. D., Clark, G. M., & Lee, S. W. (2012). The effects of using the transition planning inventory and a structured IEP process as a transition planning intervention on IEP meeting outcomes. *Remedial and Special Education*, 33(1), 48-58.
- Rehm, R. S., Fisher, L. T., Fuentes-Afflick, E., & Chesla, C. A. (2013). Parental advocacy styles for special education students during the transition to adulthood. *Qualitative Health Research*, 23(10), 1377-1387.
- Riesen, T., Schultz, J., Morgan, R., & Kupferman, S. (2014). School-to-work barriers as identified by special educators, vocational rehabilitation counselors, and community rehabilitation professionals. *Journal of Rehabilitation*, 80(1), 33.
- Rotatori, A. F., Obiakor, F. E., & Bakken, J. P. (2011). *History of special education* (1st ed.). Emerald.
- Ryndak, D. L., Downing, J. E., Morrison, A. P., & Williams, L. J. (1996). Parents' perceptions of educational settings and services for children with moderate or severe disabilities. *Remedial and Special Education*, 17(2), 106-118.
- Scanlon, D., Patton, J. R., & Raskind, M. (2017). Transition to Daily Living for Persons with High-Incidence Disabilities. In *Handbook of special education* (pp. 718-737). Routledge.

- Schalock, R. L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities*, 15(2), 116-127.
- Schalock, R., Brown, I., Brown, R., Cummins, R., Felce, D., Matikka, L., Keith, K., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: report of an international panel of experts. *Mental Retardation*, 40(6), 457-470.
- Schalock, R. L., Verdugo, M. A., Gomez, L. E., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, 121(1), 1-12.
- Schlossberg, N. K. (1981). A model for analyzing human adaptation to transition. *The counseling psychologist*, 9(2), 2-18.
- Shandra, C. L. (2011). Life-course transitions among adolescents with and without disabilities: a longitudinal examination of expectations and outcomes. *International Journal of Sociology*, 41(1), 67-86.
- Singer, G. H. S. (2002). Suggestions for a pragmatic program of research on families and disability. *The Journal of Special Education*, 36(3), 148-154.
- Smith, T. B., Oliver, M. N., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257-261.
- Snell-Rood, C., Ruble, L., Kleinert, H., McGrew, J. H., Adams, M., Rodgers, A., Odom, J., Wong, W. H., & Yu, Y. (2020). Stakeholder perspectives on transition planning, implementation, and outcomes for students with autism spectrum disorder. *Autism: the international journal of research and practice*, 24(5), 1164–1176.
- Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, 18(4), 228-237.
- Test, D. W., Fowler, C. H., Richter, S. M., White, J., Mazzotti, V., Walker, A. R., Kohler, P., & Kortering, L. (2009). Evidence-based practices in secondary transition. *Career Development for Exceptional Individuals*, 32(2), 115-128.
- Thorin, E., & Irvin, L. (1992). Family stress associated with transition to adulthood of young people with severe disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH)*, 17(1), 31-39.
- Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health*, 5(1), 3-14.

- Verdugo, Miguel & Schalock, Robert & Keith, Kenneth & Stancliffe, Roger. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of intellectual disability research*.
- Vindrola-Padros, C., Chisnall, G., Cooper, S., Dowrick, A., Djellouli, N., Symmons, S. M., ... & Johnson, G. A. (2020). Carrying out rapid qualitative research during a pandemic: emerging lessons from COVID-19. *Qualitative health research*, 30(14), 2192-2204.
- Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition from school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. *Journal of Disability Policy Studies*, 25(1), 30-40.
- Wehmeyer, M. L. (2014). Self-determination: A family affair. *Family Relations*, 63(1), 178-184.
- Wong, V., Ruble, L., & Brown, L. (2020). “We are mama and papa bears”: A qualitative study of parents’ adaptation process during transition to adulthood. *Research in Autism Spectrum Disorders*, 79, 101650.
- Woodman, A. (2014). Trajectories of stress among parents of children with disabilities: A Dyadic analysis. *Family Relations*, 63(1), 39-54.
- Woods, A. D., Morrison, F. J., & Palincsar, A. S. (2018). Perceptions of communication practices among stakeholders in special education. *Journal of Emotional and Behavioral Disorders*, 26(4), 209–224.
- Young, John, Morgan, Robert L, Callow-Heusser, Catherine A, & Lindstrom, Lauren. (2016). The effects of parent training on knowledge of transition services for students with disabilities. *Career Development and Transition for Exceptional Individuals*, 39(2), 79-87.

Appendix A

Initial Meeting Guide

Potential Participant Name: _____

Current age of child with moderate to severe disabilities: _____

After reading the informed consent form entitled, “**Consent to Act as a Research Subject**”, do you have any questions regarding being a participant in this study?

Which interview format would you prefer?

_____ Meet at a specified location for a specified time

_____ Meet virtually via Zoom or Google Meet

Appendix B

Individual and Family Interview Questions

Thank you so much for allowing me to interview you. I'm interested to hear about your experiences through (student name)'s transition into postsecondary education and life.

If it is ok with you, I would like to audio record this interview, as it will help me to make sense of it later. You may choose to stop the interview at any time. I will not share the audio recording or the transcript with the IEP team or others in the district, and I will not use your name or identifying information when discussing it with my adviser or other students in my doctoral program.

1. Tell me about your family and life experiences with _____. (Demographics)
2. Tell me about (student name)'s experiences in the public school system through his/her years in school.
 - a. When did _____ enter into special education?
 - b. How many IEP meetings would you say that you have attended through the years? (Q1, Q1a)
 - c. How have your rights as a parent and advocate for your child been explained to you through the years either during or out of IEP meetings? (Q1, Q1a, Q2a)
 - d. Were there any specific IEP meetings when you remember it all “coming together” for _____, you, and the IEP team? (Q1a, Q2)
3. How did you experience IEP meetings throughout the school years? (Q1, Q1a)
 - a. Were you supported by IEP team members? (Q1a, Q2)
 - i. Can you tell me a time when you felt supported by the district IEP team during a meeting? (Q1a)
 - ii. Was there ever a time when you felt that a member was not as supportive as you thought (s)he portrayed? Can you tell me about that experience of “failed” support? (Q1a, Q2)
4. Through your years collaborating with school district employees, has there been any IEP team that you've worked with whom you feel truly supported you and _____, even after the meetings were over? (Q2)
 - a. What did they do to make you feel supported outside of the IEP meetings? (Q1a, Q2a)
 - b. Were there times when you felt truly “included” as a member of an IEP team? (Q2a)
 - i. What did the team do that made you feel that way? (Q1a)
5. What has been your experience with case managers through the transition to adulthood for _____? (Q1)

- a. How have case managers been supportive during and after IEP/ITP meetings? (Q1a)
6. What range of emotions have you felt while moving through the stages of transition for your child? (Q2, Q2a)
 - a. Did you feel tension or discord from any particular team members? (Q1a, Q2a)
 - b. What did a team member do or say that felt discordant? (Q1a)
7. Through your years as a parent of a child with disabilities (name disability), how do you feel that your life has been impacted in relation to personal growth? (Q2, Q2a)
 - a. Which goals for yourself have been adjusted through your years as a parent?
8. In which ways has the IEP/ITP team considered your family's social inclusion in the school and community settings? (Q1a, Q2, Q2a)
 - a. How has the team assisted you and your family's interpersonal relations? (Q2a)
9. How has the IEP team considered you and your family's emotional well-being through the transition? (Q1a, Q2, Q2a)
10. Is there anything we haven't discussed already that you would like to share?

Probes:

Why or why not?

Can you tell me more about that?

Can you think of an example of when that has happened?

You mentioned____. Could you be more specific?

Appendix C

Informed Consent

University of California, San Diego

Consent to Act as a Research Subject

Life-course Transitions in Special Education: An Exploration of Trustful and Supportive

Individualized Education Plan (IEP) Team Member Behavior

Michelle Borrelli, under the supervision of Dr. Amanda Datnow, Professor in the Department of Education Studies at UCSD, is conducting a research study to find out how family members experience IEP/ITP meetings during the transition to adulthood for their children with moderate to severe disabilities. Michelle Borrelli is conducting this research for her doctoral dissertation in the UCSD Doctoral Program in Educational Leadership. You have been asked to participate in this study because your child has recently gone through the transition from high school to post-secondary life. There will be approximately 15 participants in this study. The purpose of the study is to understand how family members perceive IEP team members' behaviors, actions, and attitudes during IEP/ITP meetings leading into post-secondary life for their child. The goal is to inform future research and understand how to best support families as their children with moderate to severe disabilities go through the transition to adulthood. If you agree to be in this study, Michelle will conduct an interview with you in order to understand your ideas.

Michelle will ask you about your experiences with school district IEP/ITP meetings and your perceptions of team member support. Each interview will take approximately 45 minutes and will be audio recorded to improve the accuracy of my notes. Interviews will take place in one of two formats: virtually via Zoom (or Google Meet) or at a location of the participant's choice. Again, participating in the interviews is voluntary, and there are no negative consequences if you decide not to participate. You can choose not to answer any question at any time for any reason. You may decide not to answer some or any questions and can stop the interview at any time or ask to erase any portion of the taped recording. You can withdraw from the study by telling me.

At the completion of the study, Michelle will write a report with the results of the study. She may also discuss the results at scientific meetings, conferences, and in research papers. The results will present information only in summary form, so you will not be identified by name. Quotes may be used in reports and presentations, but they will not be connected with specific individuals. Any information that could identify you such as your name, the community you live

in, or team member names will not be used in any reports. Pseudonyms will be used to refer to individuals, schools, and districts. Michelle will use confidential study ID numbers rather than names to record information. Only she will know which ID number refers to each participant; and, only the interviewer and a typist will hear the interviews or see written summaries of the interviews.

Research records will be kept confidential to the extent allowed by law. The UCSD Institutional Review Board may review records.

Risks: Participation in this study may involve some added risks or discomforts. These include:

1. A potential for the loss of confidentiality. However, all possible care will be taken to protect the confidentiality of your records including but not limited to keeping data on a password-protected server and following standard UCSD security protocols to maintain confidentiality. Research records will be kept confidential to the extent allowed by law. In addition to myself, the UCSD Institutional Review Board may review research records.
2. A potential risk of emotional discomfort. You may be asked personal questions about your experiences as a parent with a child who has disabilities. There is the possibility that this may lead some participants to feel some mild emotional discomfort. Please be advised that you are under no obligation to discuss any topic that makes you feel uncomfortable, and you may choose not to answer any questions that make you feel uncomfortable and still remain in the study.
3. A potential risk for feelings of frustration, stress, discomfort, fatigue, and boredom. You are under no obligation to participate in or complete the interviews. Please be advised that you may stop the interview at any time for any reason. Under California law, we must report information about known or reasonably suspected incidents of abuse or neglect of a child, dependent adult, or elder including physical, sexual, emotional, and financial abuse or neglect. If any investigator/researcher has or is given such information, he or she may be required to report such information to the appropriate authorities. Because this is a research study, there may also be some unknown risks that are currently unforeseeable.

Benefits: There will not be any direct benefit to you from participating in this study. The study, however, may identify issues related to supporting families during IEP/ITP meetings. You will be informed of any significant new findings. There will be no cost to you for participating in this study.

Participation in research is entirely voluntary. The alternative to participation in this study is no participation.

You may refuse to participate or withdraw or refuse to answer specific questions in an interview at any time without penalty or loss of benefits to which you are entitled. If you decide that you

no longer wish to continue in this study, you may notify me at any time or contact me, Michelle Borrelli via email or phone:

Michelle Borrelli

mborrell@ucsd.edu

(817) 929-6371

The researcher named above has explained this study to you and answered your questions. If you have other questions or research-related problems you may reach Michelle Borrelli at (817) 929-6371. You may call the Human Research Protections Office at (858) 657-5100 to inquire about your rights as a research subject or to report research-related problems.

___ You have received a copy of this consent document.

___ You agree to participate.

Participant's Signature

Date

Audio recordings will be used during the interviews only to improve the accuracy of the researcher's interview notes. If you give permission to be audio recorded during an interview,

please sign below. By signing below, you are giving permission only for the use of the audio recordings as described above. No other use of the recordings is permitted. You have the right to request that the recording be stopped or erased during the recording. Participation is voluntary.

_____ Yes _____ No

Your Signature _____

Your name (please print) _____