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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

PARENT PERSPECTIVES ON THEIR ROLE IN THE
TRANSITION PLANNING PROCESS OF CHILDREN
WITH SIGNIFICANT SUPPORT NEEDS

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

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

December 2020

This Dissertation by: Elizabeth Elaine Osborne

Entitled: *Parent Perspectives on Their Role in the Transition Planning Process of Children with Significant Support Needs*

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

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ABSTRACT

Osborne, Elizabeth Elaine. *Parent perceptions of their role in the transition planning process of children with significant support needs*, Published Doctor of Philosophy dissertation University of Northern Colorado, 2020.

Legally coordinated transition plans have been the expectation since the Individual with Disabilities Education Act of 1990 (IDEA, 1990). Research is firm that parent participation and high expectations are evidence-based practices supporting improved outcomes in post-secondary environments (Mazzotti et al., 2016; Test, Mazzotti et al., 2009). Yet, these two expectations, which should work synchronously, often seem to be out of sync. This qualitative phenomenological study aimed to give voice to the parents of children with significant support needs (SSN; Colorado Department of Education, 2017). The researcher explored the parent's perceptions in the transition planning process, specifically evaluating their role in the process, including probing feelings of self-efficacy and collaboration. The research questions:

- Q1 How do parents perceive their roles in the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the Individual Education Program (IEP) transition paperwork?
- Q3 How do perceived feelings of self-efficacy or knowledge of the transition process of students with significant support needs contribute to the desire to collaborate?

The study's format was three focus groups of 12 parent stakeholders who were asked, through semi-structured questions, to reflect on their lived experiences of the transition process for their child with significant support needs (SSN). The group transcriptions were coded through the constant-comparison method and axial coding. Within the determined categories of

Collaboration, Self-Efficacy, and Parent Role five Main Themes emerged: Trust, Transition Programming, Advocacy, Individual Education Program Team Roles, and Time and Toll.

The themes and associated subthemes determined the parents' perception of their primary role: advocating for their child and advocating for other families and children with significant support needs in the transition process. The parents indicated that their successes in the fight for services for their student would benefit all students. Parents reflected that once they established their role as advocates, they felt that the rest of the team respected and appreciated their input. Still, the underlying feeling of "us against them" persisted.

Parent transition input in the IEP documentation emerged as inconsistent and incomplete. Parent perception of the documentation did not align with the reality of the IEP paperwork. This deficit underlined the importance of the parent voice in the process. In order to create substantial and relevant transition plans, the primary stakeholder's voice must be represented, and for this population of students, it is the parent speaking for the child with SSN. Therefore, it is crucial their concerns and input are accurately recorded.

Finally, the parent's feelings of self-efficacy in relation to collaboration were examined. This question was examined in two parts a) increasing feelings of self-efficacy and b) the desire to collaborate. The parents felt the obtainment of transition knowledge and the knowledge application were the most difficult and resulted in significant time and emotional toll. Parents communicated increasing their self-efficacy levels was a singular and isolating experience, and the schools were not an equal partner. The aspect of self-efficacy affecting collaborative was reviewed through the lens of the theoretical framework of Bandura's (1977) Self-efficacy theory and the Collaborative Theory (Kumar & Paddison, 2000). The element of trust was the glue to positive collaboration. All parents indicated positive collaboration occurred when trust existed

with the team. Had they understood the transition process earlier and were more confident in their abilities, the collaboration levels may have increased.

This study's findings provide valuable insights regarding the perception of parents' self-efficacy in the transition process and their understanding of their roles on the transition team. There is no existing research on the parent stakeholder's self-efficacy or the specific roles they feel they play on the transition team. This study contributes to the limited existing research base, specifically targeting the parents of children with the most significant support needs and their challenges with transition IEP participation. This study's results strongly support the formation of transition frameworks helping transition teams in the future identify areas of strengths and challenges in collaborative planning, ultimately affecting students with SSN outcomes.

Keywords: parent partnerships, transition, significant support needs, post-secondary, collaboration, focus groups, self-efficacy

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Two kinds of gratitude: The sudden kind we feel for what we take; the larger kind we feel for what we give. – Edwin Arlington Robinson

I have much to be grateful for throughout this journey of the last five years. I started my trek with a simple question "What happens next?" As a teacher of students with the most significant and complex challenges, I wondered where they went and what they did after leaving my room? I have found there is not a simple or universal answer. But this adventure and those along the way have brought me closer to understanding the challenge and perhaps the opportunity to impact outcomes.

Many people have sustained me in my journey, and I could not have done any of this without them. I would not have the same insight or experiences or understanding that I now possess without their presence and support. My husband is my number one cheerleader and my rock. We made the decision to begin my doctoral program, together in the kitchen one evening after school. That discussion began the adventure. Tommy, you have been there through it all, driving me up to UNCO to spend the summers learning. You gave up our weekends and most of our holidays to allow me to study without complaint and always encouraging me. I would not be here without your strength. Maybe now we can play some golf!

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Melloy, thank you for opening up the world of leadership, giving me the tools to encourage my team's capacity while inviting all levels of collaboration. Dr. Erin Moser for being the perfect piece to complete my committee puzzle. Your insights were what my topic craved. At the end of my study, it is your area of expertise that provided the understanding of vocational rehabilitator councilors potential impact on families and students

I am grateful to my peers and colleagues for sustaining me along the way! Most especially, Heather Fitzpatrick and Andrea Suk for providing the desperately needed encouragement Zooms, giving “atta boys”, conference adventures, and being the best research team, a doctoral student could have! Colleen Kugler I thank you for seeing the value in the Beyond the Classroom and matching my depth of passion for the parent partnerships, moving the program forward and making it come to life. Jennifer Porter you have been my middle and high school colleague and partner giving feedback and coming through in critical times, above and beyond!

Thank you to all the stakeholders who strive to support and plan for the most marginalized among us. I am especially grateful to the parents, for participating in this study. It was a brave action, and I did not fully realize it's import at the beginning of this project. Not until I heard your voices did I understand more of your lived experiences and the varying yet constant levels of anxiety you experience for your most precious child. I hope I can honor you and your children's voices.

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I have been wildly blessed. I am full of gratitude for the journey and all of those who played a part. My goal now is to give back and help those whose voice is quiet, be strong, and be heard!

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CHAPTER I

INTRODUCTION

Over 30 years ago, the Individuals with Disabilities Education Act (IDEA, 1990) set collaborative transition determinations as the legal standard. The collaborative partners, also known as the primary stakeholders, are identified in the reauthorization of IDEA (2004) as the students' families, school personnel, and vocational agencies or rehabilitation counselors, and when possible, the students with a disability. This standard of collaboration is reflected in the Rehabilitation Act of 1973, recently reauthorized as the Workforce Innovation and Opportunity Act (WIOA; RSA, 2014), by supporting the sharing of resources and coordinating activities between various entities. Moreover, the spirit of the determination of collaborative plans for a coordinated set of activities is reflected in the Carl D. Perkins Career and Technical Education Act of 2006 (U.S. Department of Education, 2006). The Carl Perkins Act does not directly include parents in its collaborative expectations but does aim to strengthen connections between secondary and post-secondary environments through specifically aligned planning of career and technology applications (U.S. Department of Education, 2006). State codes may not allow less than the federal statutes; local provisions must therefore uphold the intent of IDEA, WIOA, and the Carl Perkins Act or risk the loss of federal funding (Yell, 2016). Unfortunately, despite reciprocal federal and state expectations, studies indicate coordination may not be occurring on a level which derives satisfaction from the participants, nor are the outcomes always beneficial for the individual with exceptionalities (Fitzpatrick et al., 2018; Shogren & Plotner, 2012).

Statement of the Problem

There is evidence of a lack of collaborative reality between agencies and schools and of parents not invited into the collaborative transition process at a level that will provide ultimate benefit (Carter, Brock et al., 2012; Shogren & Plotner, 2012; Trach, 2012). Plotner et al. (2018) suggested stakeholders' understanding the roles of fellow stakeholders could lead to more communication which in turn would precipitate additional collaboration. Unfortunately, it is evident there is generally little understanding or knowledge about the characteristics of fellow stakeholders or what they contribute to the transition process (Plotner et al., 2018). There have been few studies comparing the perceptions of all stakeholders in the roles and responsibilities of each other; in other words, little is known about what each member of the team feels the other members contribute to the process. Nor has there been any study that has examined the level of training of participants, specifically the training opportunities, either school-based or self-initiated, of the parents. There have been no studies that focus solely on the parent's feelings of self-efficacy or personal effectiveness in transition planning for students with significant support needs. And, while clear communication and clearly defined roles and responsibilities are vital in successfully coordinated transition planning (Noonan et al., 2012), little research is available which measures parents' perceptions of collaboration and their satisfaction levels of the process.

Purpose and Rationale of Study

The purpose of this study was to examine parent perspectives on their role in the transition planning process of children with significant support needs. Additionally, the study explored how the level of collaboration, knowledge of the transition process and self-efficacy with the process may affect parent's level of participation. The study examined the parents' perceptions of roles and responsibilities in the transition process. This research on the topic sheds

light on the impediments to a coordinated model of transition in which parent stakeholders participate to maximum benefit. The research reveals differences in role perception among different groups of stakeholders, specifically the parents, highlighting the conceptions that could improve communication and collaboration. The results of this study illuminated feelings of self-efficacy and confidence in understanding the process, leading to additional partnering opportunities for parents and school personnel as well as outside agencies. Ultimately, coordinated training designs could strengthen the model of collaborative transition planning for students with SSN, leading to improved post-secondary outcomes.

Research Questions

The following research questions will be addressed in this study:

- Q1 How do parents perceive their roles in the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?
- Q3 How do perceived feelings of self-efficacy or knowledge of the transition process of students with significant support needs contribute to the desire to collaborate?

Definition of Terms

Transition: Transition is the process of preparing individuals for life beyond the required system of public education to post-secondary environments (Oertle & Seader, 2015).

The transition plan: A plan which facilitates the shift from school to post-secondary environments, based on students' abilities and interests. The transition plan should improve the outcomes of students in the post-secondary environments and "prepare them for further education, employment, and independent living" (IDEA. 1990).

The Individualized Education Program (IEP): A written program for each child/student with a disability. The plan is reviewed and revised at a minimum of annually by the IEP team

(i.e., parent, general education teacher, special education teacher, administrator, diagnostician, and various related services or instructional services personnel, as appropriate) to ensure free appropriate public education (IDEA, 1990).

Free Appropriate Public Education (FAPE): Requirement of providing a free, appropriate, specialized instruction, services, and supports provided at the cost of the public (school). Education meets standards and is appropriately provided within the public-school environment per IEP (IDEA, 1990).

Stakeholders: The stakeholders are those who are directly or indirectly affected by a program. They should be involved in all aspects of a program or project (Sellers et al., 2013). They are the “individuals whose participation is required to sustain the activity” (McGrath & Whitty, 2017. p.740).

Evidence-Based Practices (EBP): Activities or strategies which have proven to be effective based upon methodology responsive to the issue, are of high quality, and are based in scientific evidence (Odom et al., 2005).

Significant Support Needs: Currently, there is not a universally accepted definition for the individual with significant support needs (Giangreco, 2011). Derived from research and the author’s inclusion criteria students with SSN are those individuals (a) needing to take alternative state assessments or be excused from the state assessment (Kleinert et al., 2015) and/or (b) requiring significant support needs in a variety of domains, including but not limited to academics, behaviors, medical, physical, communication, daily living skills, and/or social and adaptive behaviors (Kurth et al., 2012). As part of the research criteria for this study the students may be non-verbal and communicate through non-conventional means such as facial expressions or state changes. Often, the individuals

will be at the sensory-motor or preoperational developmental stage as described in Piaget's Theory of Development (Piaget & Cook, 1952). Students with SSN are not expected to experience post-secondary environments without continued caregiver support in most areas of life, including education, independent living, and vocational opportunities (Colorado Department of Education, 2014).

A Brief History

Early advocacy for the rights of individuals with disabilities began to gain momentum in the 20th century. Several groups led the call for equal treatment or even the acknowledgment that individuals with disabilities deserved opportunities, including access to education. The Council for Exceptional Children, founded in 1922 by higher education faculty and students, led the first movements, organizing at the state and federal levels (Evans, 2017). The organization currently known as ARC (formally known as The Association for Retarded Citizen, ARC/USA) began in the 1950's and is led by families and parents of individuals with disabilities (ARC, 2020). Past and present stakeholder advocacy groups such as ARC, effected significant change and continues to influence local and federal law regarding individuals with disabilities within the public realm. It was not until the mid-20th century that the political light was shone on discriminatory practices affecting education institutions. *Brown v. Board of Education* (1954) opened the door for all children previously discriminated against to access education within the same brick and mortar structures without regard to race, color, or disability (Yell, 2016).

The Supreme Court ruling in *Brown v. Board of Education* (1954) regarding the illegality of segregated schools for all students ignited the realization in special needs advocacy groups and families of the legal responsibility for children with disabilities to obtain an education within the public-school setting. The court case of *PARC v. Commonwealth of Pennsylvania* (1972) set

the foundation for more inclusive environments for children with disabilities and reinforced that the 14th Amendment protects the education of all children. This ruling determined that the earlier education occurred in a child's life, the better for the child (including pre-school children). Turnbull et al. (2016) reiterated education is not exclusive to academics and children with intellectual disability are best educated in programs most like typical peers, and FAPE must be provided.

The watershed ruling in *Mills v. Board of Education of District of Columbia* (1972) supported the interest of the student by defining and assuring due process and procedural safeguards. In essence, the court ruled the child with disabilities must be provided FAPE, an IEP, and due process procedures. These non-negotiables became the basis and principles of special education law (Alexander & Alexander, 2012). Historically, and, in general, parents of children with SSN have fought to obtain and maintain outside resources and direct support for their children's education (Hewitt & Larson, 2007). Maintaining and supporting the intent of current legal mandates and progress in the law for which stakeholders advocated can support collaboration beginning in the initial stages of IEP transition planning. This collaboration of all stakeholders including parents and outside agencies could proactively intercept and address post-secondary support issues.

Current Acts and Laws

As the court rulings began to define the rights of all individuals the legislators were taxed with developing laws to guide and support the rulings. The Civil Rights Act of 1964 became the bedrock upon which integration and inclusion were built. Though initially seen as a case addressing segregation practices based upon race and skin color, the special education advocacy groups quickly recognized the Civil Rights Act's (1964) application towards individuals with

special needs. Almost simultaneously, the first rendition of the Elementary and Secondary Education Act 1965 (ESEA) was signed by President Johnson, providing funding to states, specifically targeting poverty. A year later, the ESEA was amended to include funding specifically for the education of students with special needs and disabilities. In quick succession, the following 10 years brought forth several additional life-altering legislative acts, including the Education of the Handicapped Act of 1970 (EHA), which increased funding to states for special education programming, provided teacher training resources, and created local resource centers. The Rehabilitation Act of 1973-Section 504 was passed next, which specifically prevented discrimination of qualified individuals from accessing activities or programs made available to typical peers in entities receiving federal funding and set parameters for post-secondary employment (Rehabilitation Act, 1973).

The Rehabilitation Act and Workforce Innovation Opportunity Act

Throughout the years, with increased advocacy group accomplishments around rights, supports, and accommodations, the Rehabilitation Act (1973) experienced several revisions. The U.S. Department of Education (2006) reported most of the revisions focused on Section 504; first developing regulations in 1977, which influenced the Americans with Disabilities Act of 1988 and 1990. The amended Rehabilitation Act of 1993 and 1998 aligned with the Individuals with Disabilities Act (IDEA, 1990) and mandated the coordination of the school personnel and the vocational rehabilitation counselors (VR). While these amendments strived to create an environment to encourage cooperation, they did not explain how to prepare individuals with disabilities to meet the challenges of the post-secondary environments of employment, living, continued education, and community involvement. Oertle et al. (2013) observed that though the intent of the revisions was admirable, a survey of stakeholders, including VRs and community

supporters, revealed that the atmosphere of collaboration and joint planning does not occur consistently. Mandating coordination and cooperation do not necessarily ensure its occurrence. The reauthorization of the Rehabilitation Act in 2015 resulted in the Workforce Innovation Opportunity Act (U.S. Department of Education, Office of Special Education and Rehabilitative Services [OSERS], 2017). The Workforce Innovation Opportunity Act (WIOA, 2014) is a joint effort by the Department of Labor and Employment and the Department of Education to establish a cohesive and relevant framework to address efforts to initiate all youth into the workforce, including those who historically have struggled for access to competitive and integrated employment (OSERS, 2017). The WIOA affirms the critical need for collaboration between VR, State Education Agencies (SEA), Local Education Agencies (LEA), and Federal entities in the creation, training, and delivery of plans to develop career pathways.

Summary

The first chapter of this manuscript introduces the study. The rationale presented reflects the concern based upon current research that though the law is clear in the expectation of collaborative transition teams, reality may fall short of intent. A brief history outlined the progress toward access to school environments for students with disabilities, and the impact advocacy groups have had on the process.

The first chapter provided important definitions with which the layman may be unfamiliar and could be essential in conveying critical aspects of the study. The research questions presented are calculated to provide insight into the perspectives of parents who are or who have recently participated in a transition planning process.

Chapter II includes a comprehensive literature review, outlining specific components within the transition program, and research supporting the study. The theoretical framework

providing the foundational support and blueprint to the research and topic is explained and reviewed prior to revisiting the research questions. Chapter III discusses the Methodology, including a description of participant recruitment, the research design, and analysis procedures. Considering this study is qualitative in nature, a section of trustworthiness is also included in Chapter III. Chapter IV outlines the predicted organization of the data results, and Chapter V includes the discussion, limitations, and future research.

CHAPTER II
REVIEW OF LITERATURE
Transition Program

Post-secondary transition services for all individuals with disabilities must achieve specific parameters set forth by the IDEA (2004) and the WIOA (2014). The transition plan is a “coordinated set of activities” between all stakeholders (IDEA, 2004).

The purpose of the transition plan is to facilitate the shift from public school to post-secondary environments, based on students’ abilities and interests (IDEA, 1997). The transition plan should improve the outcomes of students in the post-secondary environments and “prepare them for further education, employment, and independent living” (IDEA, 1990) Furthermore, the 1973 Rehabilitation Act, reauthorized as WIOA in 2014, supports the individualization of the transition programs, specifically identifying marginalized groups of students, those with “most significant disabilities,” as being assumed to be able to participate in post-secondary work activities (WIOA, 2014). Available research indicates individuals with significant support needs require targeted interventions to scaffold functional, developmental, and academic skills to support and improve the quality of life after graduation (Seo et al., 2017). According to WIOA (2014), one of the reasons individuals are not participating to the most significant extent possible in post-secondary opportunities (i.e., work or community involvement) is the lack of training or supports to meet post-secondary expectations of participation in employment, independent living, and community involvement. The training needed to become successful in post-secondary environments should be provided by the transition plan created through the collaboration of

stakeholders (i.e., parents, school personnel, and outside agencies; IDEA, 2004). However, despite these mandates, research reported that students with intellectual or developmental disabilities (I/DD) have lower transition outcomes than students who do not have I/DD (Simonsen & Neubert, 2013).

Collaboration in creating the transition plan should begin as early as possible in the child's educational career and is best achieved through a collaborative model (Trach, 2012). Beginning transition in early childhood could be an effective method of intervention to ensure all students are living in and contributing to society to their highest potential (Kohler, 1996; Trach, 2012). The Office of Special Education and Rehabilitative Services (USDE OSERS, 2017) reaffirmed transition planning can begin earlier if the IEP team indicates there is a need, and requires collaboration with families, schools, and outside agencies (e.g., vocational rehabilitation counselors). However, the evidence shows collaboration and sharing of professional competencies are not occurring with consistency within the IEP transition planning teams (Plotner et al., 2012). Moreover, perceptions of efficacy, personal and professional roles and responsibilities, and adequate collaboration have not been measured through analysis of input from all groups of stakeholders.

Teachers and Outside Agencies

Interagency collaboration has been identified as a significant predictor of transition success by preventing non-completion of school and increasing post-secondary gains (Test, Fowler et al., 2009). Therefore, teams should be intentionally sharing information and working together when creating transition plans. While input from all stakeholders has been determined to be best practice, school personnel provide the most significant contribution to the transition planning process regardless of the mandates of collaboration (Trach, 2012). Special education

teachers typically create goals and determine supports for students with little input from rehabilitators, because the rehabilitators are not routinely invited to participate in the planning process (Trach, 2012). However, teachers may be unclear about developing goals relevant to post-secondary life (Landmark et al., 2013). Despite findings that vocational rehabilitation counselors have a greater understanding of the transition process and their role (Plotner et al., 2018), the communication to determine how to best share information remains inconsistent and spotty (Trach, 2012). While special education administrators and vocational rehabilitation supervisors recognize the need for collaboration, the actuality of participating in collaborative activities is infrequent, and the staff is not appropriately trained (Oertle et al., 2017). It is problematic that professionals are concerned about their self-efficacy and are not collaborating consistently or with fidelity. Yet, students are continually moved from an entitled system of supports to an unentitled system, even though the transition plans may not address the actual post-secondary needs of the student (Gibbons et al., 2015) or legal mandates. Parents may not understand that the public education system is considered entitled. It is in this environment that IDEA (2004) sets forth protections and legal provisions protecting the family and child. Whereas, unentitled systems include the post-secondary environments which are no longer tightly regulated through IDEA and accountability factors are diminished. Analyzed through these realities, it becomes critical that the parent must take an active role in post-secondary planning.

Stakeholder Training

IDEA (2004) dictates professional development for teachers, and the determination of related services and supplementary aids for students is “based on peer-reviewed research to the extent practicable.” Studies reveal neither the VR nor the classroom teachers feel they received

adequate training within their preparatory programs on evidence-based practices (EBP) to address the transition needs of all students (Oertle et al., 2013; Trach, 2012). Teachers reported receiving limited EBP transition training in preparatory programs and received most of their training during professional development, often presented in one-shot workshops (Ludlow et al., 2005; Mazzotti & Plotner, 2016; Oertle et al., 2013; Ryndak & Kennedy, 2000). Teacher preparatory programs were found especially insufficient and inconsistent in addressing the instructional methodology of the significant support needs population (Morningstar et al., 2018; Ryndak & Kennedy, 2000). Especially concerning is that based upon research cited, for the past 20 years, teachers have expressed the same frustration at the lack of relevant training.

Ironically, the VRs also reported receiving most of their training on the job (Mazzotti & Plotner, 2016). While there has been research conducted to determine the perceptions of collaboration between teachers and direct support transition specialists (i.e., outside agencies) (Plotner et al., 2018) and research determining the efficacy of teacher and VR training (Plotner et al., 2017), little has been discussed regarding how the school personnel and vocational rehabilitation counselors feel about the responsibilities of parents or guardians during the transition process or vice versa.

Much of the existing research does not explicitly focus on students with SSN, yet does maintain that consistent parent involvement within the school environment, including input in transition programs and IEP development, is a predictor of improved outcomes in a student's post-secondary success (Hirano et al., 2016; Newman et al., 2011; Test, Mazzotti et al., 2009). Furthermore, Hirano and Rowe (2016) examined and confirmed the importance of the parent/guardian's involvement in education planning for the student. However, there is a dearth of research pinpointing parent training regarding the transition of students with SSN. Specific

trainings could strengthen the school to home collaborations which are vital for student success and even more so for students with SSN (deFur, 2012).

Based upon the lack of focused research on access to transition training for parents of children with SSN, it is imperative to delve into this area further. Another motivation for thorough research into the area of transition planning is the realization that individuals with SSN may be living longer. While there is evidence that individuals with disabilities, specifically intellectual disability or developmental disability (ID/IDD) and Down's syndrome, tend to have higher mortality rates than typical populations, these individuals survive longer than in past years (Hosking et al., 2016). There is also evidence of a decreasing mortality rate of children born significantly prematurely, regardless of neurodevelopmental impairment (Noelle et al., 2017). Therefore, the life expectancies of populations of individuals with SSN and low-incidence disabilities could be increasing due to medical technology (Glick & Fischer, 2017; Noelle et al., 2017). Thus, additional research targeting the needs of the parents of students with SSN will assist in transition planning, and the provision of necessary post-secondary supports to meet the anticipated needs of this population.

Research concentrating on parental training for students with SSN transitioning to post-secondary environments is limited at best; we are guided to best practices of collaboration by research, though limited, targeted studies. For instance, the evidence-based practices of in-home parent trainers and IEP determined related services, integrated within the transition model can help to bridge the gap from school to home (Division for Early Childhood, 2014). While the Division for Early Childhood (DEC) specifically denoted the in-home parent training and a transition model of collaboration as an EBP, these same EBPs should be extended and utilized for the entirety of the student's years in public education. Multiple theoretical/conceptual models

of transition support the collaboration of all stakeholders throughout the entire educational process with consistent school-facilitated parent and staff trainings, and active communication of future outcomes and goals (Hirano & Rowe, 2016; Kohler, 1996; Osborne & Kugler, 2019; Trach, 2012).

Evidence-Based Practices

Students with the “most significant support needs” defined by multiple disabilities, sensory-motor learners, intellectual disabilities, and specific syndromes may become additionally marginalized by inappropriate transition plans and post-secondary preparation models (Ward et al., 2016). Currently, transition plans are mandated by IDEA to begin no later than the age of 16. According to Kohler (1996), transition plans beginning at the earliest opportunity (i.e., early childhood or elementary) will assist the child in acquiring skills needed to support success in post-secondary environments. An effective method of intervention to ensure all students are living and contributing to society to their highest potential is an evidence-based model of transition beginning in early childhood (Hirano & Rowe, 2016; Kohler, 1996; Osborne & Kugler, 2019; Trach, 2012). Each of the models presented by cited authors has maintained certain EBPs of a collaborative process:

- beginning as early as possible,
- stakeholder training,
- consistent communication,
- parent involvement,
- advocacy,
- and future planning.

The Office of Special Education and Rehabilitative Services (USDE OSERS, 2017) reaffirmed transition planning could begin earlier if a need is indicated by the IEP team, and requires collaboration with families, schools, and outside agencies (e.g., VR, community partners). Additionally, the reauthorization of IDEA (2004) aligned with No Child Left Behind (2001), which focused on accountability through science-based practices. Turnbull (2005) summarized that IDEA dictates both professional development for teachers and the determination of related services, and supplementary aids are “based on peer-reviewed research to the extent practicable” (IDEA, 2004). Additional discussion on the specific conceptual models will occur later in this chapter.

EBPs related explicitly to the transition of students with SSN are limited; however, this is not to say transition or instructional teams should not endeavor to utilize aspects of EBPs, implementing them where appropriate (Cook et al., 2014). In order to implement the EBPs, stakeholders should be trained in their use. However, a study conducted by Mazzotti and Plotner (2016) revealed this might not happen to the desired extent. The authors responded to increasing demand for appropriate transition services with foundations in EBPs. To measure the reality of the practice, the researchers delivered an online survey to a comprehensive representation of transition service providers: VRs, school-based, and state and local education agencies; of the 592 usable replies, 80% of the respondents were school-based. The study requested the participants to rate their use and knowledge of EBPs for the transition process, utilizing terms *Always*, *Often*, *Sometimes*, and *Never*. They were asked to rate their acquisition of EBPs through the terms of *Agreed*, *Strongly Agreed*, *Disagreed*, or *Strongly Disagreed*. The study divided EBPs into categories: Self-Determination and Self-Advocacy, Academic Instruction, Life Skills, Employment/Job Skills, Social Skills, and Family Involvement (Mazzotti & Plotner, 2016). The

results were a mixture of reassuring and concerning findings. It was concerning the majority of the participants did not report consistent EBP training from their university-based preparatory programs (68%). As for school-based personnel, a minority received training from their districts or within their campus professional development; in fact, 56.3% indicated they never received the basic training (Mazzotti & Plotner, 2016). The encouraging results reflected the majority of providers—both VRs and school-based—were utilizing EBPs with the students. An average of 75% of the time some implementation of EBPs occurred. The survey indicated most providers received training through professional journals; in other words, self-taught (Mazzotti & Plotner, 2016). The results showed a need to provide relevant continuing education for those involved in the transition process. The need to address transition in provider preparation classes was evident. The study showed the teachers and VRs demonstrated the will to utilize the EBPs but that it was a struggle to acquire the training. Mazzotti and Plotner (2016) observed that lack of appropriate EBP training was reflective across all participants. This finding could reinforce the premise that joint and ongoing trainings with stakeholders is beneficial to develop relevant transition plans which eliminate the uncertainty of and ensure the use of crucial EBPs. Professional development or cooperative trainings could eliminate the uneven application of the EBP of coordinated transition planning, per Test, Fowler et al. (2009).

Utilizing transition frameworks to capture the specifically identified EBPs may help to inform and incorporate all stakeholders in successful transition processes and lead to improved outcomes for students with disabilities (Trach, 2012). Identified EBPs which positively affect post-secondary outcomes include

- active parent involvement throughout the child's education;
- connection to outside agencies to facilitate work, education, and living opportunities;

- opportunities for community or employment involvement before graduation;
- access to the general education environment to the greatest extent possible;
- direct instruction in self-determination and self-advocacy (Test, Mazzotti et al., 2009).

These determined actions reflect previous research (Carter, Brock et al., 2012; Papay & Bambara, 2011; Simonsen & Neubert, 2013) and could support the determination of the need for continuous and consistent parent involvement in order to impact outcomes, regardless of the disability. Snell-Rood et al. (2020) indicated parents' active involvement in transition planning of students with Autism Spectrum Disorder (ASD) improved IEP goal scores. Wehman et al. (2015) discovered high parental expectations positively influenced post-secondary outcomes. The emphasis on the need for collaborative stakeholder planning, specifically emphasizing parent participation, can be surmised from each of the presented EBPs, especially as the parent and the child are the two stakeholders who will foreseeably remain unchanged in the transition from school to post-secondary environments (deFur, 2012).

Post-Secondary Outcomes

According to the U.S. Department of Labor (2017), the latest statistics for youths with disabilities reported 42% of individuals with a disability are employed in some manner, in stark contrast to the 74% of individuals with no disability aged 20-24. However, for the data which tracks individuals throughout their life, statistics are even more disheartening, especially if the student has a cognitive disability. Per Butterfield (2015), the employment rates for individuals with any disability is 33.6%, and for individuals with a cognitive disability, the rate drops to 23.4%, but the type of employment, whether part-time, supported, or group, was not stated. These statistics do not incorporate individuals who are institutionalized (Department of Labor,

2017). It is a challenge to track employment rates for individuals with disabilities, in part due to the broad definitions of disabilities and types of work (Shogren & Plotner, 2012). For example, Shepard (2019) identified disability subgroups using descriptive abilities (i.e., self-care difficulty and independent-living difficulty) with individuals who demonstrated difficulty in self-care, reporting a 17% employment rate, but the type of work was not described. Butterfield (2015) contended that unemployment among individuals with disabilities was increasing. Data from Cornell University (2018) reinforced Butterfield's (2015) assertion: Cornell University's Disability Statistics estimated only 12.9 % of individuals with a work limitation were employed. This number has been in decline since 1990 when a high of 28.8% of individuals with a disability were employed. It is interesting to note that coordinated transition planning per IDEA began in 1990. Unfortunately, it seems the legal mandate for collaboration has not significantly influenced the obtainment and maintaining of employment (Disability Statistics, 2017).

Test, Fowler et al. (2009) indicated agency and school collaboration was an EBP which impacts the employment rates of students with disabilities and parent involvement improves post-secondary outcomes through school completion, but this does not seem to translate in national statistics. The disconnection in collaborative planning could be a result of the research to practice gap or knowledge translation. In other words research reveals what works, but stakeholder are not benefiting from the findings. Research related to models of transition for students with SSN are often conceptual rather than actual. However, it is recognized that students with SSN may not be able to participate in competitive employment (Sulewski, 2010). Thus, to maintain the legal mandates and the quality of life for individuals with SSN, community involvement and volunteer opportunities have been given greater focus than competitive employment (Rossetti et al., 2016). For this reason, it is crucial that parents be included in the

planning and creation of opportunities. These are the caretakers who will, in the end, be responsible for continuing to plan post-secondary activities (Rossetti et al., 2016) and should be provided knowledge of available resources (Hirano & Rowe, 2016). Research supports the critical piece parents provide to students with SSN, specifically in active community involvement, advocating outside agency support, and creating opportunities for independence outside caregiver input (Rossetti et al., 2016). School and outside agency service providers cannot control actions beyond their reach. Parents understanding of their role as active planning participants is invaluable, necessary, and imperative for their child's success (Hirano & Rowe, 2016).

Shogren and Plotner's (2012) analysis of the National Longitudinal Transition Study-2 revealed a lack of collaboration between agencies, especially with student's whose eligibility determination was ID and Autism. Instruction for these individuals focused on life skills and functional skills but did little to prepare them for outside work or continued education post-secondary (Shogren & Plotner, 2012). This lack of application of skills anticipatory of continued learning or employment leads the reviewer to conclude that though the student's preferences may have been considered, an application toward work skills for post-secondary employment was not consistently evident. Though the language of both IDEA (1990) and WIOA (2014) specified considering student's preferences when determining goals, employment, and living activities, they did not specifically state how to apply the transition plan.

Stevenson and Fowler (2016) illustrated collaboration between VR and school personnel by each understanding more about the transition assessment used by schools and the discovery processes used by the VRs and then communicating to fill the gaps each process revealed (i.e., discovery focused on employment and assessment focused on independent living, education, and

employment). However, this process still left the family or parent as a non-facilitating participant. The VRs and school professionals request information from multiple sources, including families, but this could leave the parent waiting to be contacted and possibly overlooks the education of the parent in the transition process and provision of resources. With all the research and EBPs it seems that something continues to prevent true stakeholder collaboration.

Parental Involvement

IDEA (2004) indicated family participation in transition planning as an essential part of the student's success in the transition process as the families are constants in the student's post-secondary life. Consistent parental involvement within the school environment, including input in transition programs and Individual Education Program (IEP) development, was a predictor of improved outcomes in a student's post-secondary success (Hirano et al., 2016; Newman et al., 2011; Test, Fowler et al., 2009). However, there is little guidance on exactly how parents are to specifically participate in the transition planning process and if the parents fully understand their role in the process.

Legal and theoretical precepts call for the active engagement of the parent, but parent voices are rarely presented in research and primarily limited to the parents of students with high incidence disabilities or those whose children are expected to be employed. A comprehensive search of the literature revealed minimal results focused solely on the parent of a child with SSN and their feelings of self-efficacy or their feelings of satisfaction with the transition planning process. Furthermore, of studies conducted regarding parent perceptions of the IEP planning process, most reported parents' feelings of trepidation and uncertainty (e.g., Cavendish & Connor, 2017; Zeitlin & Curcic, 2014). Parents, regardless of the child's disability, reported feelings of frustration about the IEP meetings, often manifested by being presented paperwork

that appeared to be completed without their input and feeling more alienated when disagreements arose (Tucker & Schwartz, 2013). MacLeod et al. (2017) reported parents felt they had value to contribute in knowing their whole child and expressed the desire to be allowed to share their knowledge in educational planning. Yet, often, they still felt the need to “constantly advocate, and fight” for the services and resources they felt their child needed (MacLeod et al., 2017 p. 396).

It is evident that the transition IEP planning process may be falling short of expectations. This paper is meant to help clarify parental barriers, successes, and expectations around this critical planning period which may affect the remainder of the child’s and family’s life within the post-secondary community. Before a successful process can be actuated it is vital to give voice to the parent stakeholders who will be perpetuating the plan long after the school has graduated the student. This study will endeavor to identify the self-efficacy perceptions of the parents to participate in transition planning and implementation, their confidence in their own abilities, satisfaction with collaborative actions with other stakeholders, and the perceived outcomes of the efforts of the team as a whole. In order to accomplish this feat, parental involvement and roles must first be examined.

Access to Involvement

Rossetti et al. (2016) conducted one of the only studies on students with SSN, focusing on parents’ active participation in the transition planning process. The study found three contributing factors to student success in post-secondary environments. The three themes were (a) self-determination can exist through parents’ interpretation, (b) parents need to be intricately involved in the educational process, and (c) direct service providers and functional collaboration are imperative in positive transition planning. These concepts helped ensure all members were

part of the initial planning process, which increased the ability to proactively intercept post-secondary support challenges.

Though the parent and student participation are expected and stated in the federal legislature, reinforcement is not a vital occurrence in the statutes. Rather, once again, the language is suggestive rather than declarative. Active student participation in IEP meetings was reported as very low across disability categories, but for those students with ID or autism, the number was even lower, 3.3% for students with ID and 2.6 % for students with autism (Newman et al., 2011). Wagner et al. (2012) urged schools to encourage active participation in transition planning, especially teaching students to self-advocate and understand the supports they need since students transition from an entitled environment into an unentitled environment in which they need to self-advocate (Gibbons et al., 2015).

Barriers to Involvement

A recent analysis by Hirano, Rowe et al. (2018) illuminated potential barriers to parent involvement, which refocused the lens to a wider systems barrier rather than individualized constraints. The analysis highlighted three primary categories: (a) family barriers, (b) school barriers, and (c) adult service barriers. For families, many of whom were low-SES or minorities, barriers included limited access to resources and a lack of knowledge in navigating existing education systems. Though Hirano, Shanley et al. (2018) did reflect that often systemic issues such as lack of healthcare and social services may impact family engagement, as meeting basic needs would take precedence. School barriers also revealed perceptions of racism and prejudice with the schools not seeming to value cultural differences, and schools not sharing information about transition or transition planning beginning too late. It was noted that beginning transition planning in high school did not give adequate time for parents or students to prepare for post-

secondary environments (Hirano, Shanley et al., 2018). The last barrier to adult service consisted of low expectations of the individual's abilities, perhaps preventing the student from reaching true potential. The review recognized the lack of agency service opportunities or resources as a key impediment to meaningful work participation. But some VRs felt students should receive some job training within school environments, rather than primarily through vocational agency support (Hirano, Shanley et al., 2018). However, schools are not required through IDEA to provide job training or pre-employment training. This reality could shed additional light on the gaps in stakeholder collaborations.

Another study by Cavendish and Connor (2017) supported Hirano's findings and suggested parents did not feel heard and were delegated to a "passive" participant role in which they were told what the plan for their child would be (Cavendish & Connor, p. 38). Primarily, the only engagement came in the form of the parent being asked if they had any questions. School IEP members seemed to be checking boxes for legal compliance. Unfortunately, 10 years earlier, similar results of parents as non-active participants were discovered by Landmark et al. (2007), who cited barriers included parental knowledge and meeting planning times. What seems to have improved in the decade was the parent understanding of the law. Landmark et al. (2007) reported at that time most parents were unaware of their rights, especially culturally diverse parents.

A current study by Kurth et al. (2019) examining IEPs for parent involvement revealed less than favorable results, indicating parents' concerns were not addressed via goals. Members of the IEP teams were excused, some before giving relevant input. These findings could suggest a lack of understanding of the roles and the consideration of input from all team members to be vital to crafting an appropriate plan.

Francis et al. (2016) suggested parents of children with and without disabilities felt inclusive school culture was a driving factor in the family-school partnership. However, research has highlighted that being cognizant of roles and expectations of stakeholders within the transition planning process has been insufficient (Oertle & Seader, 2015). Research conducted to determine the perceptions of collaboration between teachers and transition specialists (Plotner et al., 2018) and research determining efficacy of teacher and VR training (Plotner et al., 2017) as well as studies identifying individual stakeholder's understanding of roles and responsibilities (Plotner et al., 2012) have revealed areas of disconnect and concern. So, even though school to home collaborations are vital to student success and even more so with the SSN population (deFur, 2012; Yell, 2016), there still appears to exist a disconnect in consistent family-school partnerships (Fitzpatrick et al., 2018; Trainor, 2017).

In a study examining parents' understanding of the roles of vocational rehabilitation counselors when the school provided parents with additional training, beyond the packet or brochure of resources, and delivered information in multi-formats, including face-to-face, parental contact with outside agencies increased (Young et al., 2016). Parents also reported most of the transition planning occurs within the IEP meetings (Shogren & Plotner, 2012). If this is the only opportunity parents have to collaborate or give their input, the spirit of collaboration is not being met (Turnbull et al., 2006). Therefore, parents may not receive targeted or relevant training in the transition process to be able to participate to the most significant extent possible in collaborative transition planning. Thus, participation should exceed the bounds of merely utilizing student and family preference. The families must be active participants and explicitly taught the skill of engagement (deFur, 2012).

Parent Involvement: The Law

One of the non-negotiables in serving students under the Individuals with Disabilities Act (IDEA, 2004) is the mandate for collaborative transition planning. The statute is absolute in its requirements, if not specifically definitive:

- (a) Transition services means a coordinated set of activities for a child with a disability that (1) Is designed to be within a results-oriented process..., (2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes (i) Instruction; (ii) Related services; (iii) Community experiences; (iv) The development of employment and other post-school adult living objectives; and (v) If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation. (IDEA, 2004)

IDEA Part B outlines indicators of compliance in fulfilling requirements of IDEA. The eighth indicator of Part B uses specific language to determine participant involvement and the expectation of parent involvement in the process: "facilitated parent involvement as a means of improving services and results for children with disabilities" (20 U.S.C. 1416(a) (3) (A)).

IDEA (2004) provides several methods in which the parent can meaningfully participate in the IEP planning, including procedural safeguards of prior written notice, notice of IEP meetings, and the consideration of parent input. And, while IDEA does specify inclusion and consideration of parental input within the IEP, what it does not clarify is the method or the scope of parent involvement in determining transition services. The transition planning committee and IEP committee must determine the services needed for all children, including children with low incidence disabilities (LID) and SSN. IDEA does not explicitly define the roles or responsibilities of the different team members. Though it can be inferred from IDEA's

requirement for parent involvement to the greatest extent possible during the IEP process, families and caregivers are not specifically mentioned as a required member for transition planning. However, neither, according to the reauthorization of IDEA in 2004, does an external support agency need to be an active participant in the transition IEP meeting. While a representative must be invited, if the provider is unavailable, their presence is not required (IDEA, 2004) The current interpretation of IDEA 2004 seems to place the burden of effective and efficient transition planning squarely as the responsibility of school personnel (Trach, 2012).

Despite these inconsistencies and vague language in the legal definition of transition, universally held and supported by the Office of Special Education Services- Ideas that Work (2016), participation of each of these representatives of post-secondary life, including school, families, and outside support agencies, is imperative for a successful transition into environments after formal education. IDEA mandates meaningful parent participation throughout the IEP process. This statute, therefore, by default, includes transition services. The parent or caregiver will most likely be constant in the students' life and is the entity closest to the students. According to Pleet-Odle et al. (2016), parents hold high expectations for their students and their outcomes. However, a general disconnect for many schools is integrating parents into the educational process (MacLeod et al., 2017; Test, 2012). The parent role is critical with all students with disabilities. However, students with SSN require a specialized inquiry to determine how impactful and to what extent the parent's role influences outcomes (Rossetti et al., 2016). Transition services for students with SSN may translate differently than other less impacted students (Shogren & Plotner, 2012).

IDEA makes clear that parent inclusion within all aspects of the IEP is the legal standing. Parents are required members of the IEP team. While all team members are vital to the IEP

discussion, the parents should take special precedence. All measures should be taken to ensure their full participation and equal weight bestowed upon their input (IDEA, 2004). Court cases have established this precedent in the verdicts of landmark decisions. Ensuring all team members are present and the parent's input is solicited and considered is a piece of the procedural requirements judged as the first part of the Rowley case, indicative of providing FAPE (*Board of Education of the Hendrick Hudson Central School District v. Rowley*, 1982).

If the team fails to establish cohesion in which parent input is considered it could be considered a denial of FAPE. This has been upheld in multiple court decisions, including the determination in the *Paso Robles* case in which the parent expressed multiple concerns about appropriate evaluations and provided documentation to substantiate their concerns, but were still ignored by the district (*Timothy O. v. Paso Robles Unified Sch. Dist.*, 2013). Hence, active parental involvement cannot be overlooked or minimized. The parent's participation is also not just a courtesy, the school district must prove they have come to the table receptive and willing to consider parental desires. However, areas of disputed interpretation may surface in that though the parent is a contributing member of the team, the district is not required to implement the parent suggestions (*R.L. v. Miami-Dade County School Board*, 2014). It is essential that the stakeholders (i.e., teachers, administrators, and parents) understand not only the directives behind the laws but also the intent and "Why" of the laws, which is, ultimately, to improve the quality of life for all people.

Models for Parent Involvement

Research supports creating transition frameworks beginning in early childhood (Hirano & Rowe, 2016; Kohler, 1996; Osborne & Kugler, 2019; Trach, 2012). To facilitate the trajectory into post-secondary environments as early as possible the child with disabilities should be treated

no differently than any other typically developing child (Kohler, 1996). Society begins asking the typically developing child, “What are you going to be when you grow up?” at a very young age. The same question should be asked of all children, perhaps especially the child with SSN since the planning process for this population is more intensive and requires a multitude of specializations (Seo et al., 2017). Transition planning for students with SSN should begin much earlier than the mandated age of 16 (Papay et al., 2015).

In order to create an atmosphere of productive engagement various models of collaboration have been proposed. Kohler (1996) presented one of the landmark theoretical taxonomies which linked previous research to practice. Kohler’s research identified family involvement in the transition process as key component in a successful transition into post-secondary life. Within the overarching involvement 34 practices were identified and placed into three areas of focus: (a) family involvement, (b) family training, and (c) family empowerment (1996). Kohler et al., (2016), Taxonomy 2.0 provided additional guidance, including updated specifics of Family Involvement (i.e. cultural acknowledgements and parents involved in the entire transition planning process). While Family Empowerment maintained original intent, Family Training was renamed to Family Preparation and additional indicators were introduced in Taxonomy 2.0 (i.e high expectations and advocacy). Direct correlations of family empowerment and family input can be drawn to the reauthorization of IDEA (2004) and mandates put forth therein regarding the consideration of family input and the requirement of family participation. However, IDEA does not directly address the need for family training. Models of collaborative transition, two of which we will discuss, address this non-legally mandated need.

Analyzing previous parent involvement, Hirano and Rowe (2016) acknowledged most models encouraged parent involvement at both the school and home levels and environments. Typical standards of participation included school communication, going to IEP meetings, and expressing their desire for the student's transition outcomes. Hirano and Rowe (2016) concurred these were necessary and appropriate but felt expansion, the accurate and inclusive definition of parent participation, was needed to maintain the parent's active involvement during the prime transition years, primarily high school. Examining parent input, traditional models, and the predictors of transition success, the author's suggested model of parent transition is conceptual in scope.

The Hirano and Rowe (2016) model emphasizes the integration of traditional models of academic, transitional parent participation as a science-based predictor of successful transition, and the anticipated continual involvement of parents post-secondary. Additional parent training supported this model presented in a multi-dimensional manner, becoming active in the process through a variety of channels. It requires the collaboration of outside agencies to guide the parent in appropriate post-secondary opportunities, taking into consideration the parent's persistent role in the child's life. This conceptual model leans heavily on parents fully understanding the options available to their child and how to become an intentional and efficient advocate for the child. The model is dependent upon a system change within the school environment. The school's values must align with the belief and support of the parental efficacy and expectations; Figure 1 illustrates the top-down approach of the Hirano and Rowe (2016) parent-driven model. Initially, administrator, teacher, and school professional community buy-in is key to the success. The teachers must maintain their efficacy and then pass their knowledge and skills to the parent (Hirano & Rowe, 2016; de Fur, 2012). In so doing the parent is emboldened to utilize

interventions, EBPs, and specialized instruction, and in turn, becomes the instructor, assessor, advocate, and facilitator. These steps are in preparation for transition planning. Embedding collaborative convictions within the system will assure transition which incorporates school, families, and service providers.

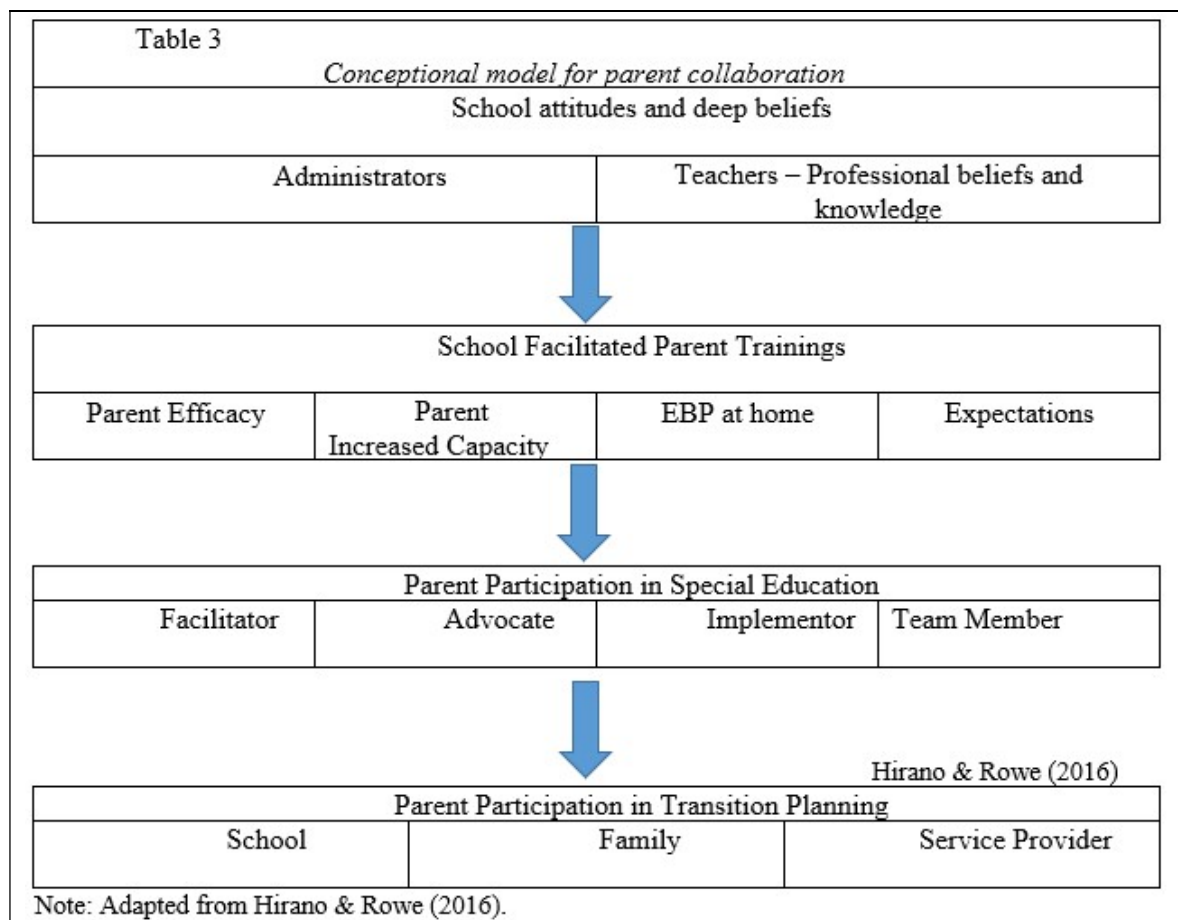


Figure 1

Conceptual Model of Parent Participation in Transition Process

Hirano, Shanley et al. (2018) went further to validate a parent model of participation by conducting an additional factor analysis, the results of which supported the previous model, thus, reinforcing the previous research of the necessity of parent active involvement within the transition planning process to affect positive post-secondary outcomes (Papay & Bambara, 2014; Test, Mazzotti et al., 2009).

Parent Roles within the Transition Planning Process

Based upon the aforementioned research it appears the definition and parameters of the role of the parent fall into two categories, conceptual and reality. Without a blueprint and specific guidelines of the abilities and obligations of the parent within the transition process, teams are left to their own devices. IDEA (2004) provides protections and rights but not necessarily responsibilities of the parent stakeholders. The spirit of IDEA is for full and equal participation of the parent within all aspects of planning for transition. However, the disconnect seems to lie in the implementation of the law's intent and the understanding of role responsibility. Parents reported feeling like an outsider in the process and that they were not taken seriously (MacLeod et al., 2017; Zeitlin & Curcic, 2014). Schools felt they were shouldering the burden of transition planning (Trach, 2012) and that, at times, parents were disinterested in the process (Mapp & Hong, 2010). VRs reported feeling they were not consistently invited to the table (Plotner et al., 2012). Thus, the uncertainty of responsibility and the lack of understanding of personal and other stakeholder roles emerged as a possible impediment to a cohesive and functional transition team.

Commonalities of best practice regarding parent roles have emerged from the research. Parents should be invited into planning early by the schools so as to develop relationships and an understanding of the process (Papay et al., 2015). Parents' first-hand knowledge of their children as the "whole child" were able to provide information other stakeholders were not privy to (MacLeod et al., 2017, p. 391). In planning for a student with SSN the supports will be unique and specialized (Seo et al., 2017), requiring as much information as possible to create a functioning, sustainable plan. Therefore, it is more important than ever that the parent participate, optimally, during the entire planning process. The goal of this paper is to uncover

some additional impediments or reinforcers to parents operating as full team members, setting goals, and sustaining outcomes. The study will encourage the parent to define their current role in the process and to share their perceptions of their roles and actions which might affect their roles in the transition process.

IEP Documentation of Parental Involvement

Under IDEA 2004 each student must have an educational program that is calculated to provide educational benefit, as follows: Individualized education program, or IEP, means a written statement for a child with a disability that is developed, reviewed, and revised in accordance with §§300.320 through 300.324. This mandate was firmly established in the *Rowley* case. In this precedent-creating decision a two-part rule was established: (1) Procedural steps must be followed and (2) the IEP should be “reasonably calculated to enable the child to receive educational benefits.”(U.S. 187-204, p. 458.) Application of these rules can help determine if FAPE has been provided. Intentional and focused construction of the required elements of the IEP ensure the educational plan will provide the prescribed educational benefits mandated by law (*Board of Education of the Hendrick Hudson Central School District v. Rowley*, 1982). And, while all team members are vital to the IEP discussion, the parents should take special precedence. All measures should be taken to ensure their full participation and equal weight bestowed upon their input. Ensuring all team members are present and that parental input is solicited and considered are procedural requirements judged as crucial to providing FAPE. However, as the previously cited research demonstrates parent participation in the IEP process is often inconsistent. An examination of parent involvement in the IEP meeting was conducted by Kurth et al. (2019), which documented whether parent input was evidenced through corresponding IEP goals. The study did not focus specifically on transition input; however,

results were important in the collaborative process and outcomes, generally speaking. Kurth et al. (2019) found the key elements included parents feeling they were routinely outnumbered by school personnel, which might not be surprising based upon the related services and supports students with SSN often require. However, the study also highlighted the discouraging statistic that approximately 1/3 of the time parent concerns were not addressed concretely through IEP actions (goals or services) and that parent concerns at other times were disputed or dismissed. These results did not seem to encourage parent continued involvement or collaboration in the IEP process and could have impeded participation. No current literature was found concretely reporting parent participation in the transition process through document analysis.

Theoretical Framework

Examining the perceptions of the parent/guardian as a stakeholder in transition planning required combining or intertwining theories to support the multiplicity of levels, including the feeling, conscious and unconscious, of self-efficacy. It was critical to examine how these feelings may impact parent participation in the transition planning process and the collaboration of parents within the team framework. The combination of Bandura's Self-Efficacy Theory (1977) and the Collaborative Theory (Kumar & Paddison, 2000) emerged as cooperative theories needed to facilitate successful partnerships and bonded parent-teacher relationships. The ethos of collaborative planning is all stakeholders having a part in the decision-making process (Healey, 1996). Ensuring the parent stakeholders, a place at the table, fully equipped with the necessary materials and information to be able to communicate impactfully, contributes to the essence of collaboration (Woods et al., 2018). In turn, this might impact the satisfaction of the parent regarding the transition process. The element of trust, while perhaps not the center of

Collaborative Planning Theory, is nonetheless essential to productive collaboration (Kumar & Paddison, 2000).

Bandura's Theory of Self-Efficacy (1977, 1994) outlines personal perceptions of the ability of oneself to accomplish tasks or be proficient in an endeavor; "Self-efficacy beliefs determine how people feel, think, motivate themselves and behave" (p.2). Bandura (1994) outlined four precepts influencing these beliefs. The first is obtaining success in a pursuit. The more difficult the endeavor the greater the feelings of self-efficacy. Second is social modeling. When people observe peers accomplishing an action, they are more likely to feel they themselves can accomplish the same feat. Individuals can also increase feelings of self-efficacy through "Social Persuasion" (Bandura, 1994, p.3). Hearing encouragement from others or an expressed belief in ability can transfer to inner confidence and faith in self-achievement. And lastly, people's feelings of emotional regulation can affect levels and degrees of accomplishment or capability. Therefore, "mood also affects people's judgments of their personal efficacy. Positive mood enhances perceived self-efficacy, despondent mood diminishes it" (p.3).

Hence, utilizing aspects of the Collaborative Theory, allowing parents to participate fully in transition planning, and giving equal weight and consideration to parents' knowledge-base and input will precipitate opportunities of inclusive conversations. At the same time, this may present an opportunity to learn together, implementing social modeling, social persuasion, and providing support for each member of the transition planning team. The incorporated model of the intertwined theories (see Figure 2) gives a visual representation of the foundation and framework of the resulting blueprint leading to success.

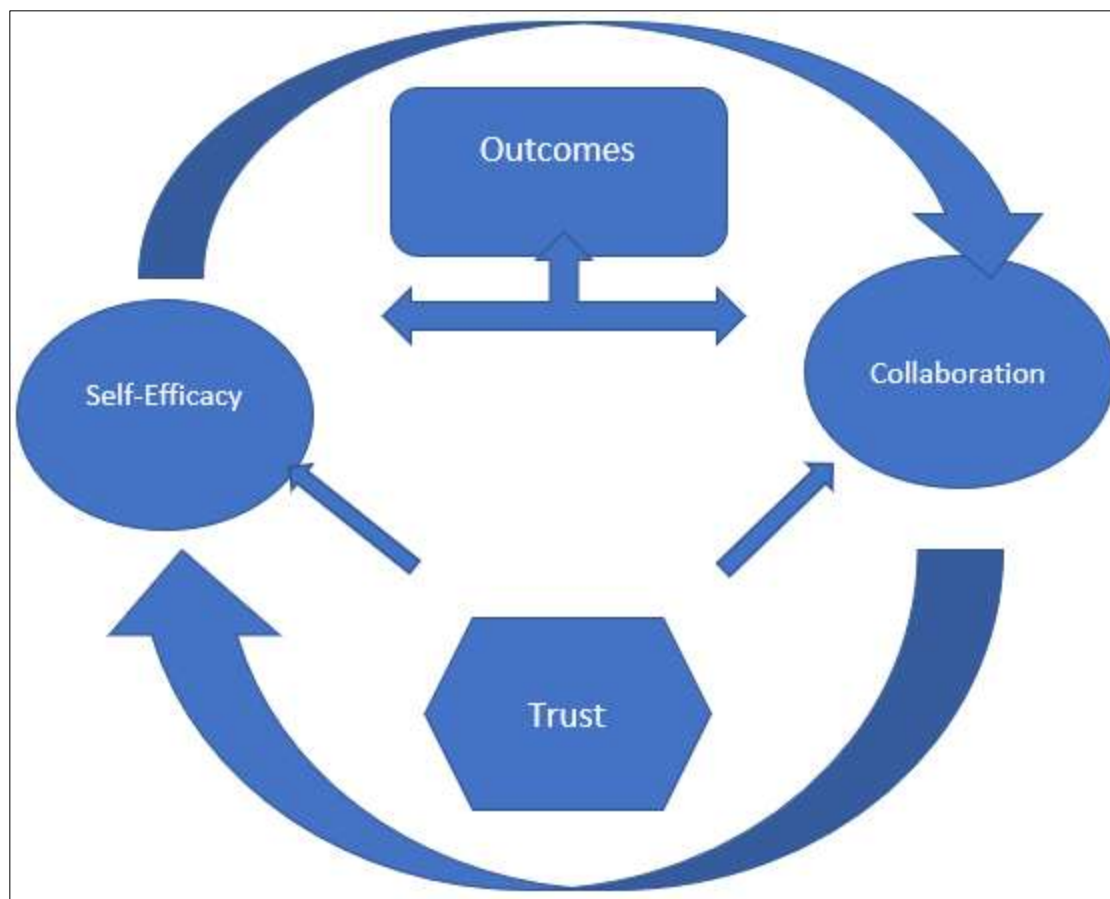


Figure 2

Incorporated Theoretical Model of Collaboration Theory and Self-Efficacy Theory

Note: Interaction of stakeholder feelings of self-efficacy driving collaboration. While simultaneously elements of collaboration drive the increased feelings of parent self-efficacy. Mediating factor of trust comes into play as the glue. Ultimately the interplay of collaborative actions and self-efficacy affect postsecondary outcomes (Osborne, 2020)

Summary

Parent participation is a required component of IEP planning. Not only is participation best practice it is legally mandated to document efforts of involvement by multiple statutes, including IDEA (2004) and WIOA (2014). As transition planning is an element of the IEP it can be assumed that invited parent participation is mandatory. Court cases have upheld the expectation of parent involvement in creating the transition plan. Rulings from the bench have determined lack of parent involvement can constitute a violation of FAPE (*Timothy O. v. Paso*

Robles Unified Sch. Dist., 2013) and/or a procedural violation. Yet, despite the mandates and the legal support, reported levels of parents' collaboration in the IEP planning process is less than comprehensive (Blackwell & Rossetti, 2014; Fitzpatrick et al., 2018). While previous studies upheld that parent involvement improved student outcomes in post-secondary environments (deFur, 2012; Papay & Bambara, 2011; Ruble et al., 2019), no studies examined the perceptions of parents of students with SSN and their level of self-efficacy, types of collaboration, and feelings of confidence with the process.

Models of collaboration have been presented, but many of these are conceptual and theoretical in nature and have not seemed to bridge the research to practice gap. Parents have reported feeling overwhelmed with the amount of paperwork required and the intricacies of obtaining post-secondary resources (Fitzpatrick et al., 2018), but there is little additional evidence about parents' personal feelings of self-efficacy or comfort with their roles as transition team participants. In fact, while IDEA set forth Procedural Safeguards as protections for parent participation, there is no research or universal guidelines on how the parent is expected to participate, other than giving their input.

The purpose of this study was to explore parent perceptions of their role within the transition process, contributions, feelings of self-efficacy, and how parental perceptions guide collaborative actions and satisfaction outcomes.

CHAPTER III

METHODOLOGY

Methods and Analysis

The intent of this study was to examine the parent perspectives on their role in the transition planning process of children with significant support needs. Parent participation in the transition process as well as maintaining high expectations in general have been determined to increase post-secondary outcomes for students with disabilities (Carter, Austin et al., 2012; Mazzotti et al., 2016; Test, 2012).

Included in this chapter are the researcher's stance and methods. The researcher's stance gave context to the motivation of the study. The stance also revealed any biases or predilections of the researcher conducting the study. Reporting the researcher's stance contributed to trustworthiness and added validity to the process (Creswell & Miller, 2000; Kozleski, 2017). This chapter includes a discussion of participant characteristics, recruitment, the research design, data collection, and analysis of the data. A section on trustworthiness illustrates the researcher's efforts to maintain validity in the findings through evidence-based processes determined to preserve validity and credibility.

Researcher's Stance

In qualitative research it is suggested the researcher have lived experience of the phenomenon they are exploring (Brantlinger et al., 2005). In order to address the possible subjectivity and reflexivity within a work, she must hold to a reflective practice of acknowledging existing values and beliefs (Lichtman, 2014). Therefore, as the researcher I

presented my conscious values and experiences within my stance. I intentionally planned for researcher reflexivity, which enhanced validity and the trustworthiness of the project (Brantlinger et al., 2005; Creswell, 2013; Lichtman, 2014)

I have worked in public schools for the past 12 years. Prior to public education, I worked in a private early childhood school for one year, teaching the three-year-old class. My true passion is for individuals with exceptionalities, focused on children with SSN. I was a special education instructional coach and department chair for a middle school (six years) and currently serve in the same role in a high school. The first five years of public education service were spent working directly with students with SSN in a classroom setting, and I still work closely with parents and teachers who serve the needs of students with SSN.

While in the classroom, I was impacted by the social and academic growth of this population of students when they were taught based upon the evidence-based practices (EBP) of Jan van Dijk (1967) and the techniques learned from Millie Smith (2005), a consultant for the American Printing House for the Blind. Watching the students' achievements, I began to consider their post-secondary options for continued learning, work, and community involvement. I was alarmed at the lack of transition planning in the school district for children within the developmental classrooms and I became more cognizant of the very limited options for students with the most significant disabilities. I want the individual's growth and learning to continue, not come to an abrupt halt after 18+ programming. Unfortunately, based upon my experiences, more often than not these young adults end up at home with a toddler toy or, in the worst-case scenario, in an institutional facility. My desire is to help provide other options through early transition planning.

After being accepted into the doctoral program at University of Northern Colorado, I began to read national and international research. An understanding grew that the concern I have for students in my own district was replicated in the majority of schools around the country and the world. Opportunities to conduct research with other students arose as did opportunities to present at conferences. Participating in conferences, it became evident the need for more relevant planning and coordination was not an isolated occurrence. I have developed a collaborative transition framework, which is the foundation of most of my presentations. I feel it is imperative to begin transition planning as early as possible, meaning upon identification of a disability or, often, in the case of children with SSN, at birth.

My biases also manifest in the one-to-one contact I have had with the children as a teacher and as support personnel. I have cried with frustrated parents about the obstacles they face in acquiring the needed resources for their children. At the same time, I have represented the school in disagreements about services parents have requested. I understand the passions which drive both of these stakeholders and it is for that reason I think it is essential to discover what the perspectives are of the stakeholder who will be responsible for the post-secondary success of students with SSN—the parent. I believe that it is through qualitative research that a lived experience can be truly vetted and, perhaps through that examination, solutions can be found and progress that impacts outcomes can be made.

A significant part of my research has focused on marginalized populations and the supports in place for these students, including examining the perspectives of all stakeholders who support students with SSN. I plan to continue to work with and for populations which are often not the primary focus of the educational communities.

Recruitment

Upon approval by the University of Northern Colorado Institutional Review Board (IRB) (see Appendix A), I began participant recruitment. The requirements of a phenomenological study are the shared, lived experience of a group of people (Creswell, 2013, Merriam & Tisdell, 2017). Therefore, a purposeful sampling design was used. Patton (2015) maintained that purposeful sampling is a result of isolating what is uniquely uncommon amongst a group of people; hence, the parents of a student with SSN were purposefully selected due to their unique yet common experiences.

The two types of purposeful sampling used were snowball and convenience sampling procedures. Convenience sampling entailed recruiting participants based on their availability, including time, location, and determined sample number needed (Merriam & Tisdell, 2017). Singularly implemented convenience sampling might have negatively affected the credibility of the study and encouraged possible biased results (Merriam & Tisdell, 2017). Snowball sampling involved locating a participant and asking that participant to suggest to others or pass on the opportunity to participate in the study to others who meet the same criteria (Patton, 2015). The combination of these two examples of purposeful sampling lent credibility to the sample and was used to recruit parents/guardians by word of mouth to participate in focus groups.

Parents/caregivers were recruited from a southwestern state and were parents of students with SSN needs. An initial request for participants was sent to the administrators of three special needs support groups, explaining the parameters of participation (i.e. parent of a child with SSN and participation in transition planning) and the researcher's university contact information (see Appendix B). These groups were support groups for parents whose children were on the autism spectrum and/or significant support needs. The administrators of the support groups were

provided with scripted information and recruitment request (see Appendix C) to post on their social media sites. The recruitment request contained a link to the informational letter and consent (see Appendix D). The parents were informed they were providing consent in accessing and completing the survey. I reached out to known parents who met the participant requirements through an email with the recruitment letter. These participants responded to the recruitment letter and were directed to a participation link within the letter. The link led the participants to the demographic questionnaire (see Appendix E) and provided the self-efficacy scales (see Appendix F).

The participants' children represented different levels in the transition process, from first-year participants to the second year out of 18+ programming. All students were individuals with SSN, many of whom had involved health complications, behavioral challenges, or comorbidity of exceptionalities. Per the parent reports, none of the students were expected to be competitively employed without direct supervision or participate in a typical workday or week.

Participants

The participants of this study were legal guardians of a student with SSN aged 13–23 at the time of transition, who had participated in the IEP transition planning process within the past five years. Their students attended a public school or charter school bound by federal IDEA parameters in grades eight through 18+ programming. I posted a recruitment request on three social media parent support sites. The group sites were geared specifically for parents whose children could have SSN. Participants responded to the recruitment request through a participation link embedded within the request, which included a more detailed overview letter, consent form, collected demographic information, and self-efficacy scales.

Exclusionary questions were included at the beginning of the questionnaire in an attempt to maintain the inclusion criteria of the participants: “Are you the parent or guardian of a child with significant support needs” and “Have you been on a transition IEP team for students with significant support needs in the last five years?” If the responses were respectively “yes”, the demographic questionnaire continued. If the answer was “no”, the survey ended with the message, “Thank you for your participation. At this time, you do not fit the criteria of the study.”

The demographic questions (see Appendix E) were accessed after the participants met the exclusionary criteria. Demographic information provided an overview of the participants to control for possible extraneous variables, which increased the validity of responses (see Table 1). The participants included 10 women and two men within the age ranges of 40-60 years with a variety of educational levels. The participants overwhelmingly lived in a suburban environment, though one participant indicated rural living. All of the participants had a child who was currently or had recently participated in the transition process, and all children had SSN.

I utilized focus groups which captured responses and illuminated answers to the research questions. Focus groups were best utilized when the subject was of a common interest and a familiar topic for all members (Merriam & Tisdell, 2017). The advantage to focus groups was that the participants could “cue or prompt each other in ways that an interviewer...is not able to do in a one-to-one interview” (Remler & Van Ryzin, 2015. p. 73).

Initially, the focus groups sizes were expected to be two groups of six, however due to scheduling conflicts I ended up hosting three focus groups. The first group had four participants, the second group had five participants, and the third group had three participants, for a total of 12 participants. In each focus group one parent participated via Zoom. The range of participants still met the viable target for focus groups numbers based on manageability, organization, and ability

to record all responses (Jayanthi & Nelson, 2002). Three focus groups assembled with four, five, and three participants, respectively, created a comfortable number to thoroughly vet the topic and allowed all voices to be heard. Larger groups of greater than six would have proven more difficult to manage even participation (Jayanthi & Nelson, 2002).

All participants were assigned a number and any personally identifying markers were eliminated or disguised immediately following transcription of video, to encourage honesty of responses. Focus group sessions were videotaped with permission in order to match participants with responses and to capture every single person's statements.

As a common characteristic, in each focus group, the participants spontaneously introduced themselves to each other and began chatting, seeming to make common connections. In the second focus group, three of the participants recognized each other, but were not friends. It was interesting to note that the parents started to network with each other as soon as they were seated. I believe this created a level of comfort and eased any trepidation, the acknowledgment, "I understand you...we have something in common." The mood within the room in each focus group seemed congenial and expectant.

Table 1*Participant Demographics*

Participants	Years	Gender	Ethnicity	Age	Education	Environment
<i>18+ or Post-Secondary Programs</i>						
1	7-9	Male	Caucasian	41-50	HS/Assoc	Suburban
2	7-9	Female	Caucasian	41-50	Master	Suburban
3	1-6	Female	Caucasian	51-60	Bachelor	Suburban
4	7-9	Female	Other	41-50	Prefer not	Suburban
5	7-9	Female	Caucasian	41-50	HS/Assoc	Rural
6	7-9	Female	Caucasian	41-50	Master	Suburban
<i>8th grades -12th grades</i>						
7	>1	Female	Caucasian	51-60	Master' +	Suburban
8	1-6	Female	Caucasian	51-60	Master	Suburban
9	1-6	Female	Caucasian	41-50	Bachelor	Suburban
10	7-9	Female	Caucasian	41-50	Master +	Suburban
11	1-6	Male	Caucasian	61+	Bachelor	Suburban
12	1-6	Female	Caucasian	51-60	HS/Assoc	Suburban

Setting

The focus groups were scheduled for the end of June, and concern for the COVID-19 virus was great in some parts of the country. However, the recruited participants were determined to participate in the study. Therefore, the focus groups continued as planned, albeit following all Centers for Disease Control (CDC) guidelines of social distancing, masks, and hand sanitizer. The public library was the initial location for the groups but reconsidered in light of caution regarding areas of large group gatherings. Utilized instead was a minimally used local office suite offered by the peer observer's family. This alternative provided a large private conference room which allowed for social distancing during the focus groups.

We held the meetings, two in the evening, and one in the afternoon, on three different days, based upon participants' collective preference. In preparation for the groups, I placed an identifying sign in the door "Parent Group" and sanitized all surfaces. The peer observer and I set up the tripod and cell phone to video and audio record the meeting. I used a laptop computer for each of the focus groups as one participant in each group requested to participate through Zoom. In each case, the reason centered around the parent's concern for their child (i.e., the inability to find at-home care; the child had had a rough day; immunity concerns). These predicaments illustrated the additional considerations taken when planning events outside the home as a parent of a student with SSN.

I provided a mask and hand sanitizer as each participant entered, then directed them into the conference room. Each person was given a number on the table as identification for transcription and as a pseudonym. We socially distanced around a large conference table. The videotaping commenced only after the participants were settled and the sessions began. As an additional incentive all participants were offered a bottled beverage and given an appreciation

goody bag before beginning the meeting. The goody bag contained some wrapped snacks as well as the 10-dollar Amazon gift card.

Research Design

The researcher implemented a phenomenological study. Creswell and Poth (2018) described the phenomenological study as examining the shared and common experience of a group of individuals. The researcher determined the shared experience, in this case, to be the transition planning process for students with SSN, then “develop[ed] a composite description of the essence of the experience to all individuals” (p. 75). The qualitative approach of examining a lived experience through phenomenological research design strove to capture the more intangible constructs of perceptions, experiences, and beliefs (Minichiello & Kottler, 2010).

I began each focus group with an icebreaker, introducing myself and inviting the participants to introduce their child to the whole group. I prepared questions (see Appendix G) designed to provide answers to the three research questions (see Table 2) and implemented in a semi-structured format. Dependent upon the responses I asked additional probing or clarifying questions to determine meaning of participant statements or delve further into a related topic. Per Brantlinger et al. (2005), a quality indicator of qualitative research is the researcher’s duty to illuminate and clarify participant responses that will add depth and clarity to the study, providing authentic answers to the research questions. The parent perceptions of collaboration and support received were additional factors examined and included in the coded data for this study. By analyzing the responses to the semi-structured, open-ended questions design, I established overarching themes and then deconstructed themes and revealed the common precepts (Creswell, 2013; Merriam & Tisdell, 2016), which contributed to the perceptions of the current transition models, IEP transition teams, and parent perceived roles in the process.

Self-Efficacy

The ability to understand and ability to perform through “cognitive, motivational, effective, and decisional processes is defined as a person’s self-efficacy” (Bandura, 1997, p. 2). Self-efficacy was empirically determined through the median of the responses to eight survey questions each (total of 16 questions) from two measures, the New General Self-Efficacy scale (NGSE; Chen et al., 2001a), and the Transition Specific Self-Efficacy Scale (TSSE, Osborne, 2020), which I modified to address the self-efficacy of transition planning (see Appendix F). The NGSE is within the public domain and therefore no permission was needed per PsycTESTS (Chen et al., 2001a). I piloted the TSSE version with a group of stakeholders and shared the tool with two specialists in the field of transition for additional professional feedback. Other research had utilized the NGSE or the General Self-Efficacy scale (GSE) as a general measure and modified the instrument as a content-specific scale (e.g., Cordle et al., 2016; Nguyen, 2019; Zhu et al., 2010). I mirrored this application with the TSSE created for transition specificity. Each section of the TSSE and the NGSE contained eight questions. A 4-point Likert-type rating scale was used to record responses, 1 = Strongly Agree to 4 = Strongly Disagree. The original scale was on a 5-point rating scale; however, I chose a 4-point Likert-type scale to avoid a neutral option (Chen et al., 2015). The questions were calculated to determine a person’s feeling of self-efficacy, both in general and specifically, regarding the transition process; for example, *I will be able to achieve most of the goals that I have set for myself*, and *I can give valuable information to the transition team*. The item, *In general, I am anxious about the transition process*, on the TSSE was reverse coded prior to aggregating responses. Scores on the NGSE have shown adequate reliability (coefficient α of .86 and .90) in smaller samples and unidimensionality (Chen et al., 2001b). The operational definition of feelings of self-efficacy was the median of the

responses for a possible range of 8-32 in each subscale score. It was anticipated that the self-efficacy general and transition responses would differ; thus, after statistical analysis, I compared each of the individual scale results.

Data Collection

I video-recorded each focus group session. An additional peer observer was recruited to unobtrusively record points of reference and observations during the meeting without active participation in the discussions. The peer observer was a teacher from a developmental classroom of a local high school. The observer had knowledge of the transition process and participated in transition IEP meetings. The same peer observer was used for all focus groups. The additional notes provided an extra layer of validity. Following the focus group, the interviewer recorded her thoughts, feelings, and perceptions of the interviews, including observations of participants and body language. Peer debriefing between the researcher and the peer observer occurred immediately following the focus group. We compared impressions and observations to support validity and reinforce trustworthiness, I videoed our debrief.

I transcribed the focus group discussions and the peer observer debrief using a commercial transcription service. Additionally, I asked the participants to share the most recent transition IEP with me ahead of the focus group discussions. The additional artifact of the de-identified and transcribed IEPs along with the recorded parent perceptions lent additional validity to the study and offered another dimension to the study by documenting the parents' perceptions of collaboration within the IEP meeting by the school district. Comparing the perspectives of collaboration shed light on the same or dissimilar interpretations of two groups of stakeholders (i.e., school personnel and parents) of the same event. All data was kept in the researcher's possession in a password-protected computer and locked file cabinet, as I printed the

transcriptions and IEPs to annotate and I recorded my perceptions in a notebook throughout the analysis process. All IEPs were delivered in electronic form and maintained in a password-protected file. The audio/video recordings were erased upon verification of transcripts' accuracy through a member check after the study was complete. I did revisit video recordings throughout coding to discern tone or inflection not provided by the transcriptions. The transcripts were kept in a locked file cabinet in the researcher's home office and on a password-protected computer.

The participants were contacted via the internet and email and provided information explaining both the demographic questionnaire and the self-efficacy survey, their individual rights, and a link to the survey. Qualtrics was used to administer the survey and store the data. The first survey question served as consent and contained a forced response. If the response was no, the survey ended with a statement of appreciation for their time statement. The second question established eligibility (e.g., Have you participated in a transition IEP for a child with SSN, either currently in public education including an 18+ program). Again, this was a forced response and, depending on the answer, forked to the survey or ended the application with a statement of thanks.

Data Analysis

Focus Group Analysis

In a qualitative study data analysis should occur simultaneously to data collection (Merriam & Tisdell, 2017). I used the different perspectives and assessments of data as evaluative tools. These tools included the recording of my initial thoughts immediately following the focus groups, cold reads of the transcriptions and subsequent annotations, the peer observer debrief after each session, open coding, the thematic coding between the peer-coder, and the final combining or axial coding I employed in the last stages of theme development.

For Phase 1 of analysis I immediately recorded my thoughts and perceptions of the participants and the discussion, including impressions of verbal and nonverbal communications, following each focus group. After transcription and participant feedback, I conducted a cold read, noting in the margins of the transcript my initial feelings and thoughts. I compared these reflective notes with the anecdotal notes taken immediately following the focus groups and the peer observer debrief. I read through the transcripts multiple times and familiarized myself with each participant and the tone as well as the emerging themes. I recorded my thoughts on the IEP documents as I read, taking note of all instances of collaboration and parent input within the specified transition sections. I compared the notes taken following the focus groups with the notes after reading the transcripts and the IEPs in order to ensure accuracy of data and control biases.

During Phase 2, in collaboration with the peer coder, I highlighted significant statements throughout all of the focus group transcriptions that related to the significant themes or topics of the research questions—perceptions of roles, feelings of self-efficacy, collaborations and levels of satisfaction—to develop an initial set of codes, which Creswell and Poth referred to as “horizontalization of the data” (2018, p.201). The peer coder was another doctoral student at the University of Northern Colorado in the School of Special Education, focused on students with SSN. The peer coder had experience with coding data. In analyzing the statements related to each research question, we analyzed the data for broader themes under each research question as we analyzed the data from the three focus groups. We used constant comparison to adjust for emergent themes and participant responses (Glaser & Strauss, 1967; Lincoln & Guba, 1985). I utilized axial coding, that is reflective coding, as the themes emerged (Corbin & Strauss, 2015). The initial process of coding the focus group transcripts was conducted using Google Docs for

reflection. After this individual reflection, the peer coder and I met face-to-face for three days and coded each group concurrently. Each interview was analyzed and themes allowed to emerge regarding parent perceptions of the transition process. In order to target specific, objective perceptions of parent experiences with transition planning, I used thematic analysis and response summary to provide a deeper and richer understanding of the target concept of transition planning (Swain, 2018). The peer coder and I discussed our codes, ultimately reaching 100% agreement.

After coding all of the focus groups, the data was uploaded into Dedoose software (Sociocultural Research Consultants, 2016). Dedoose is a qualitative analytic software which supports management of data and helped in the comparison of the qualitative data to the quantitative results of the surveys. Phase 3 consisted of analyzing the codes and combining coded responses into specific themes and subsets that best answered the research questions. Data which deviated from a relation to the research questions were segregated to a “miscellaneous” file for discussion or future analysis. Phase 4 entailed the joint determination of overarching categories and themes, subthemes, and areas of similarity between the peer coder and me. I then analyzed through axial coding, combining and ordering multiple subthemes, into the five major and succinct themes which ultimately emerged. Though axial coding is more often used in grounded theory, for the purpose of isolating themes from within focus groups I felt axial coding was the best fit. Thus, I ensured delineation and that there was no overlap between finalized themes and clear connections in answering the research questions (see Appendices J and K). Phase 5 of qualitative analysis focused on naming the themes, and based upon all considerations and resultant outcomes, how the themes should be organized in order to relay the lived experiences of the participants and their responses to the queries (Braun & Clarke, 2006).

Self-Efficacy Analysis

The data for demographics and the self-efficacy scales were collected via Qualtrics. Demographics were separated and reported (see Table 1). The self-efficacy scale data were prepared and uploaded into SAS analysis. To determine validity of the scale I conducted a pilot on the self-efficacy tools, both NGSE and the TSSE. The pilot sample size was four teacher stakeholder participants. I intentionally refrained from using parent participants in order to avoid possible redundancy or overlap of participants. The purpose of the pilot was to ensure relevancy of the scales and expose any unanticipated outcomes (e.g., confusion of questions, appropriate length, appropriateness of analysis). The pilot revealed the scales were sound.

For the parent I conducted a preliminary and descriptive analysis before conducting statistical tests. I examined for outliers and missing data or scores that seemed to be anomalies. There were no issues of concern in the data for the parent responses of those who participated in the study. However, on an interesting side note, I identified four surveys that had been ended with the eligibility questions and two surveys started but not completed. After preparing the data from Qualtrics in Excel, I conducted a nonparametric analysis. In Excel, I converted the responses to numeric variables. The resulting datasets were then imported into SAS. Considering the small sample size, rather than analyzing the mean, I compared the median between self-efficacy scales of all groups of stakeholders. For this analysis I tested whether there was a significant difference between the two groups using Wilcoxon rank sums test for the NGSE and the TSSE separately. I used the Wilcoxon rank sum test specifically because it is more flexible and handles small sample sizes (Woolson, 2005). I then used Wilcoxon sum test to determine a difference between general self-efficacy and transition self-efficacy. Analysis of and comparison of the levels of self-efficacy of stakeholders, self-efficacy in general and self-efficacy of the

transition process, provided for a better understanding of areas of need, responding to Research Question 3 regarding self-efficacy. In order to strengthen the understanding of the participants' self-efficacy, I compared the results of the surveys of self-efficacy to the verbalized feelings of self-efficacy within the focus group responses.

IEP Analysis

When I received the most recent transition IEPs provided by the parent prior to the focus group sessions, I de-identified the documents. I then extracted the relevant sections of the IEP: transition planning participation, including goals, supports and services, and post-secondary concerns. I conducted conventional content analysis on each section. The three focus groups' IEPs were coded together. The parent input section of the IEP and the recorded instances of collaboration, the transition parent questionnaire, and parent input within the deliberations were collected and maintained using the Google Doc program, and password protected. I read the IEP's identified sections for initial impressions, and anecdotally recorded thoughts. I extracted, analyzed, and documented all of the mentions of parent concern or input. I then compared to the comments parents had made during the focus groups related specifically to IEP documentation to determine if perceptions matched the document.

Response to Research Questions

All data gathered were coded, analyzed, and compared with the corresponding research question. Specifically, focus groups were transcribed, and based on directive questions as well as the natural flow of the conversation, parent perceptions of their current role were reported in answer to Research Question One. IEPs were analyzed for collaboration and participation in response to Research Question Two. The self-efficacy median results were compared to the qualitative themes from the focus groups to determine parent perceptions of levels of self-

efficacy, addressing Research Question Three. The following Table 2 outlines how each research question was answered per data collections.

Table 2

Research Question Data Collection

	RQ 1	RQ 2	RQ 3
Data Sources	Focus group	IEP Sections of Parent Input, Transition questionnaire, Deliberations Focus Groups	Self-Efficacy Scales Focus groups

Research Questions

- Q1 How do parents perceive their roles within the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?
- Q3 How do perceived feelings of self-efficacy or knowledge in the transition process of students with significant support needs contribute to the amount of collaboration?

Trustworthiness

I established trustworthiness to increase the validity and credibility of the qualitative study (Creswell, 2013). I took several steps in order to ensure the credibility and validity of the study. I maintained audit trails from the beginning of the process through a variety of described methods. Initially, I maintained a journal of the internal process of conducting the study. This gave me the ability to convey to the audience the mental workings and reasoning behind steps taken during the qualitative study. Upon initial review of the transcripts I wrote my perceptions and highlighted common themes in the margins of the transcripts to create a separate artifact

from the initial perceptions immediately following each session. This anecdotal trail of thoughts served as additional evidence to the axial coding and constant comparison methods used.

Following each focus group, the peer observer and I sat down and debriefed the session; each debrief session lasted approximately 30 mins. The peer observer was a teacher at the high school level in a self-contained classroom. The peer observer routinely participated in transition planning and was a member of the transition planning team for all of her students; she was knowledgeable of the processes and the law governing the transition planning. Our conversations were recorded and then transcribed. Throughout the debrief, the peer observer and I recognized similar themes that later emerged in the formalized coding: (a) teachers and collaboration, (b) the level of stress and struggles, (c) evolution of self-efficacy, (d) IEP documentation, (e) struggles with post-secondary supports, and (f) parent role. The peer debrief occurred to increase validity of findings (Brantlinger et al., 2005). Upon completion of the peer debrief the themes were reanalyzed for discrepancy and debated until a resolution of 100% agreement was reached. I recorded my own anecdotal reflections of the sessions and added to the data sources.

Adding to the elements of trust included the use of experts in research methods and in the transition field. Through the concurrent coding of all focus groups and, ultimately, reaching a 100% agreement with the expert peer coder strengthened the trustworthiness, as did recruiting an expert in the field of transition for feedback on the scales and on the proposed focus group questions.

The audio-recorded sessions were sent to a commercial transcription company. And lastly, as the second level of member check, the coded findings were sent to the focus group participants for verification and feedback in order to validate the results and provide an opportunity for correction. Member checks are considered to support validity (Creswell & Poth,

2018). I received responses from seven of the 12 participants. The member check ensured the research represented the spirit of the debate and the consensus of the participants' lived experiences (Brantlinger et al., 2005). All of the participants who responded agreed to the validity of the themes captured. Participant 3 wrote; additionally, two parents contacted me outside of the focus group. Parent 10 stayed after Focus Group Two and wanted to continue the conversation, so I recorded and transcribed the continued conversation. Parent 8 emailed me her reflection of the group and her continued thoughts of the transition process. Both parents' comments did not reveal new insights, but rather strengthened the themes identified through the coded transcripts of the focus groups. I did not use comments or thoughts outside of the focus groups within the reported data. However, the additional parent comments did serve as a type of member check and underlined the prevalent and identified themes.

Triangulation

The need for trustworthiness and validity of data analysis was strengthened through the triangulation of multiple sources. The memoing and anecdotal responses created a real-time running mental log of my initial responses and reflections. I compared the transcribed focus groups and verbalized feelings of self-efficacy to the results of the self-efficacy surveys, presenting a more authentic perception of a parent stakeholder's confidence in their knowledge and how this may translate into their participation. This brought us to the final stage of triangulation, where I compared how the parent participation within the IEP meetings was documented through analysis of the parent input and deliberations of the IEP paperwork. I then reported if documentation of IEP meeting events reflected the perceptions of the participants when compared with the transcriptions.

Summary

Chapter III outlined the methodology proposed for the study. Due to the limited number of students within in the community of students with SSN, parents were recruited through purposeful sampling, including both convenience and snowball techniques. I examined the attitudes and perceptions of parents of students with SSN through specific participant parameters.

Data collection occurred using transcribed focus groups. The most current IEPs of each student were requested and gathered from parents. The IEPs provided were analyzed for stakeholder collaboration primarily through the indication of participation and the deliberations. Additional information on each participant's feelings of self-efficacy was determined through a NGSE (NGSE; Chen et al., 2001a), and the TSSE, which I modified to address the specifics of transition planning of parent stakeholders. The administration of the scales served to activate metacognition of the participants' self-efficacy in general and regarding transition planning, prior to meeting. The results and analysis of the scales provided insight into levels of self-efficacy and differences in relation to the different constructs.

Data analysis was supported through primary researcher coding, a peer observer took observational notes throughout the focus groups and debrief followed each focus group. A peer coder was recruited, and concurrent coding of transcripts reached 100% agreement of the themes. Coding occurred with the intent of providing answers to the research questions.

Finally, considering the qualitative and phenomenological research design, artifacts of trustworthiness were determined and collected. The author maintained a journal, recording thoughts and interpretations following focus groups, coding sessions, and review of IEPs. The researcher's thoughts and perceptions were reflected in the margins and created connections

during the initial full reads of the transcripts, prior to and during coding. And, as stated above, the peer debriefs from two knowledgeable peers and the analysis of multiple data sources ensured a process of triangulation.

CHAPTER IV

RESULTS

The primary reason for this study was to shed light on stakeholder's perceptions of their role in the transition process and as a member of the IEP team. This phenomenological study implemented through focus groups, self-efficacy scales, and examination IEP artifacts provided a thick and rich description (Creswell & Miller, 2000), and profound revelation of parent stakeholders' views, challenges, and successes throughout the transition process. Further inquiry into the self-efficacy of parent stakeholders was geared towards understanding how comfortable the parent was with his/her knowledge of transition resources and where the parent obtained this knowledge. The specific research questions were:

- Q1 How do parents perceive their roles within the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?
- Q3 How do perceived feelings of self-efficacy or knowledge in the transition process of students with significant support needs contribute to the amount of collaboration?

This chapter presents the key findings from the participants and the artifacts. The organization of this chapter presents the focus group analysis and development of the themes and sub-themes through open coding and the use of Dedoose software. The next section outlines the analysis of the IEPs for specific documentation of parent input and whether the documentation in the IEP reflects parent perceptions of documented information. Additionally, the New General Self-Efficacy (NGSE) and the Transition Specific Self-Efficacy Scales (TSSE) were compared,

presented, and used to determine whether a participant's feelings of ability differed in terms of personal efficacy as opposed to self-efficacy of the specific concept or action of transition.

Thematic Analysis

The thematic analysis provided an examination of the focus group conversations from a variety of perspectives. I used the different perspectives and assessments of data as evaluative tools. These tools included the recording of my initial thoughts immediately following the focus groups, cold reads of the transcriptions and subsequent annotations, the peer observer debrief after each session, open coding, thematic coding between the peer-coder, and the final combining or axial coding I employed in the last stages of theme development. In order to maintain the purpose of the study, my questions were calculated to elicit thoughts based upon specific categories: Collaboration, Roles of the Parent, and Self-Efficacy. It was through the lens of these categories that, ultimately, the following themes emerged:

- Trust
- Transition Programming
- Advocacy
- IEP Roles
- Time and Toll

The categories, themes and subthemes are visually represented in Figure 3 to provide clarity of the coding process. Within this section, I reported the themes and subthemes and utilized the participant's quotes and narrative to support findings.

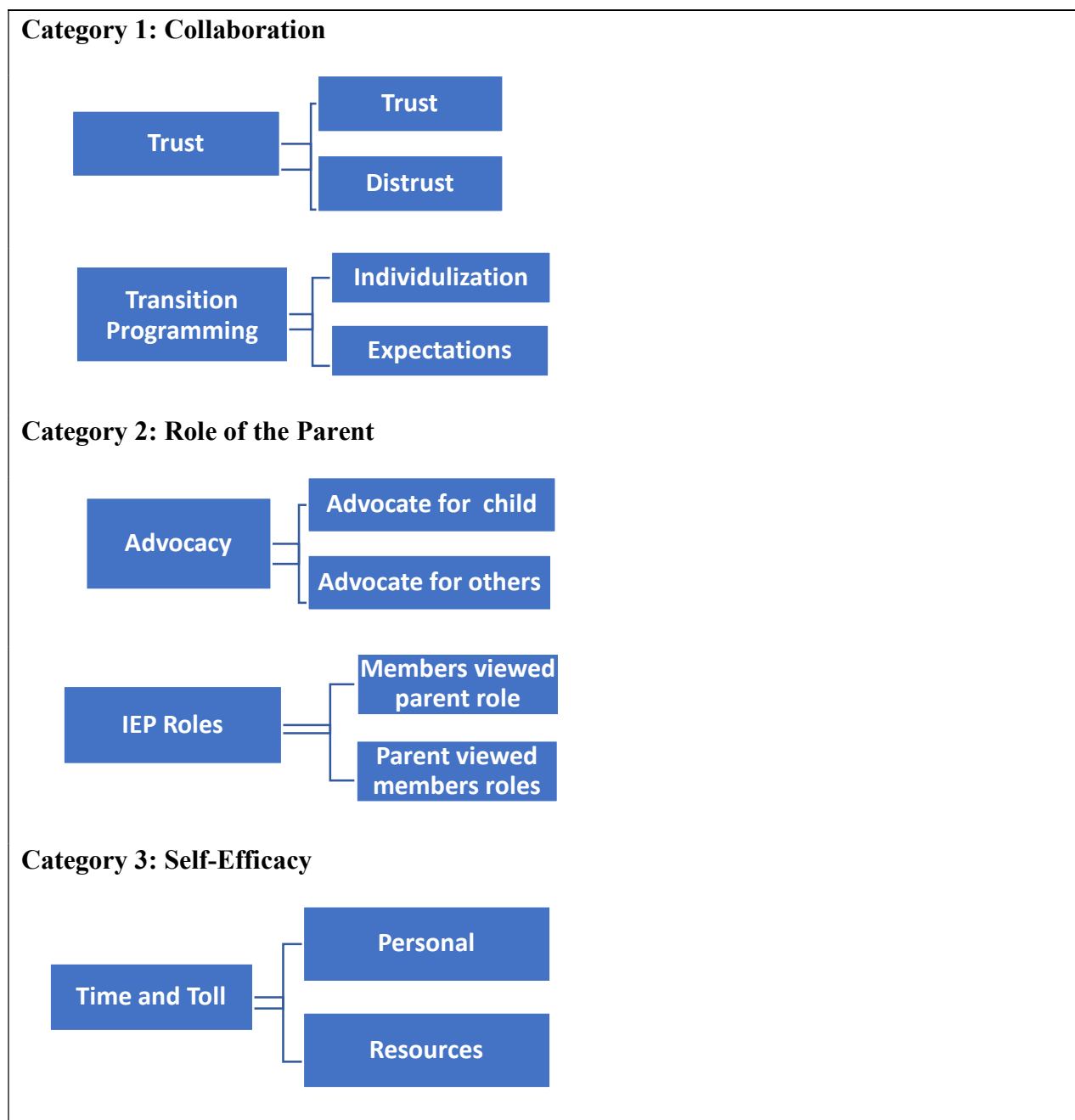


Figure 3
Representation of Categories and Resulting Thematic Analysis and Emergent Subthemes

Category 1: Collaboration

The definition of Collaboration is participants taking part in a joint project or operation (Healey, 1996). The parents reported mixed feelings of the amount and success of the collaborative transition process. Analysis of the data revealed two themes from the Category of

Collaboration: (a) Theme 1: Trust, with the subtheme of distrust, and (b) Theme 2: Programming, with sub-themes of Expectations and Individualization. Each of these Main Themes drove levels of collaboration.

The elements of trust and distrust supported the Collaborative Theory (Kumar & Paddison, 2000), which identified trust as a crucial factor in the strength and success of collaboration. The levels of trust were often different for entities (teachers, transition/IEP teams, and districts) and seemed based upon specific interactions and outcomes. Each participant reported having an overall experience which provided illustrations of both trust and distrust. In the findings, the theme of trust and identified sub-theme of distrust are detailed separately.

Main Theme 1: Trust

The facet of trust was a critical element in the successful collaboration of the current study's parents with the rest of the IEP transition team. Trust united parents in their affirmation and was a vital factor in creating and implementing an education and transition plan. The trust aspect fell into four categories: (a) trust of the teacher, (b) trust of the team, (c) trust of the district, and (d) trust and collaboration.

Trust of the Teacher

Every parent expressed that the positive experiences with the transition process stemmed from the teacher and the confidence and trust that they felt with their interactions and communications, as Parent 4 stated,

I trusted the teacher. And I was still learning. So, I knew I was part of this team, but I felt like I was part of the team because I would have seen this stuff [goals, supports] before, which you know I go through from cover to cover. But because I trusted the teacher, and the interaction was really between [the teacher] and me. So, when we came to the table, there was never an issue. And so, it was a calmer situation. And there was more trust. I felt more trust.

The trust between the parents and teachers was not necessarily easily established, but once trust had been gained, most disagreements or concerns were much easier to overcome to reach an agreement. All parents indicated that mutual trust was the glue in positive collaboration and transition planning. Parent 4 continued to express the group's feelings and thoughts,

Once that trust is established, then you have a good year because even if you don't agree on something, you don't agree on it, and you figure it out together. And then you go into the IEP meeting united... like that..., she understands that it's a team, it makes the [transition] process easier.

The level of importance given to trust in a teacher expanded to encompass the safety and general well-being of children within the classroom. The concern for trust in day-to-day classroom environments as well as in instruction and interaction was incredibly important for students with SSN who may not have the protective reflexes or the processing abilities to avoid dangers or accidents. When the parent trusted the teacher to take care of his/her child, the occasional mishap was understood as part of day-to-day possibilities, as illustrated by Parent 5,

We got a great teacher, and we're all on the same page, we're working to common goals. That's kind of when you're like, okay... And it's okay for some of us to not agree. But at the end of the day, when we did have [trusted teacher], Student 5 is in good hands, he's not gonna get hurt there. Will there be accidents? Yes, because accidents happen at church, too. There's another wild child, and they trip over Student 5 or something like that, it's okay.

When trust existed on these two critical levels—academic and physical safety of the child—the parents indicated the transition planning process in general improved, and they began

to feel more like a team player during transition planning. The parent's anxiety lessened, and collaboration could be the focus.

Trust of the Transition Team

The element of trust with the IEP transition team was mentioned less but still seemed to be an important aspect of collaboration with the transition process. Once again, the teacher and day-to-day interactions appeared to dictate the level of trust with the IEP transition team. When trust was mentioned with the team, it was associated with the classroom teacher. Parent 9 illustrated the teacher had reinforced her trust in the team as a whole; she trusted the teacher; therefore, she trusted the team, "but I think it depends on the teacher too. Y'all, I trust the [specific teacher]."

It also became clear through conversations that trust and productive collaboration of the transition team hinged on the different individuals within the team and the perceived amount of individual team member's engagement or whether the parent felt the team was actively working to benefit the child. Parent 12 discussed how the planning process could be productive in determining the necessary supports and services provided throughout the year when various team members supported parent relationships.

I did the collaboration and the input of the assistive technology guy they brought in. He was great, offering his suggestions. And actually, the APE teacher was also there...[APE] checked in on me over the summer, it was so funny. Trans Spec. was there, everyone kind of had. But they all agreed that she [child] has to have some form of communication, 'cause this is something that we've been working on her whole life....And Trans Spec. is really good; she's one of a kind, she knows Student 12, she observed her in the classroom ...I think she's better than most, and I like that she gets to know that the kids.

Ultimately, parents asserted that they experienced productive transition team collaboration after establishing trust. Additionally, as part of the mutual trust, the parents needed to feel that the team had their child's best interest at heart and listened to the parents, valuing

their opinions and input. All the participants indicated there had been disagreements and problems along the way with transition IEP teams, but that once they had established a foundation of trust and expectations, the parents felt able to accomplish common goals in support of the child. As Parent 5 observed,

Sometimes, trust can be revealed through the comfort levels of the team, and once the trust has been created and the understanding is that everyone is working in the best interest of the child, true collaboration happened...I had the best principal and a couple of other people on staff. And sometimes it was so fun, and just sitting around like the View, just a bunch of us women, we're all on the same page doing what was right for Student 5.

Trust of the District

Parents used the term “district,” but perhaps more accurate would be to clarify with the term, district administration. Trust in the district administration became more abstract, and the comments from parents became more general. Parents connected the district with funding and placement. The perception that the district was a vague entity might have supported the assumption there was no opportunity to develop the trust. However, when specific individuals (e.g., coordinators or directors) became involved, trust became more tangible. Parent 5 related an interaction with a coordinator upon entering a new district that provided her with a positive initial impression of the district. This initial impression developed a feeling of trust in “having more faith” in the district and appropriateness of placement.

And the sweetest lady [they shouldn't retire] called me and simply said, ‘Because of Student 5's low functioning, we're afraid he may be injured in life skills.’ And to me, I've always been one to put Student 5 where there's the most activity, even though he's low functioning....we went to High School, and they got it all worked out. And that individual, she was wonderful.

Additionally, parents appeared savvy in including the Special Education administration, representing the district, when not satisfied at the campus or classroom level. The comment “going to the top” was voiced multiple times in each focus group when transition teams

disagreed. “Going to the top” indicated the parents had reached outside the IEP team to the district administration. The Special Education district administrators became the mediators, with typically satisfactory results. Parent 12 explained that after success in one district collaborating directly with district administration, she used the same strategy with her new district and achieved similar satisfactory results.

But then in [district], I go right to Sped Administrator because I knew her from [another district], and I’ve never had her... I feel like she’s on my side. And I feel like I don’t have to go higher than her because I have gotten everything I’ve ever wanted this year.

Parent 12’s words indicated she trusted the district administration when individual representatives were specifically called upon to settle a dispute. In his/her experience and the experience of five other parents, “going to the top” had produced positive results.

Trust and Collaboration

Trust occurred to differing degrees with all the participants. Often, the level of collaboration seemed dependent upon the trust with the teacher. For example, Parent 6 stated,

I feel like it’s [collaboration] kind of fluctuated based on the teacher that [Student 6] had at the time. I think, early on, we had a teacher that was very active with me and planned with me, and I trusted her.

The importance and the driving factor of trust around productive collaboration for the team continued throughout the conversation of driving team collaboration. Parent 2 demonstrated this by stating,

There have been times I have blindsided them in an IEP meeting, and we have sat there. And we have spent an hour and a half revising goals, because I changed my mind at the last minute and decided I had a problem with something, but it’s always been pretty collaborative.

However, illustrating collaboration, but perhaps at a lower level of trust, Parent 8’s response indicated a consensus by the other members of the focus groups, waiting to collaborate within the meeting could be used as a power tactic to ensure meeting the needs of the child.

I've literally walked in and written out an IEP and said, "This is what I want this to look like." And then we go from there. They [transition team] may think, "There's that parent." And I'm like "Well, I want this, this and this." And oddly, that's worked well. That's an aggressive approach. But it's one way to do it.

When trust existed with the IEP transition team the parents indicated they felt comfortable collaborating within the meeting. Parents were confident that disagreements in the plans could be resolved with little to no negative feelings, as Parent 3 observed,

I mean, I think overall, like I said, it was a positive experience. I would try to just always go into meetings with an open mind, and when I did that, I usually found that I felt like they were trying their best to give her what they thought would be good for her.

When the engagement was consistent, the element of trust and feeling they were part of the team was a component of the transition IEP parents expressed approval about and felt able to express themselves with everyone working on the child's behalf.

Subtheme: Distrust

Conversely, all of the participants had experienced various degrees of distrust, which could have led to lost opportunities for productive collaboration. The subtheme of distrust contained the same elements, yet, rather than trust, the participants expressed distrust or a feeling of "us against them." The lost opportunities of collaboration fell along the same lines of teacher, transition/IEP teams, and district administration. Noted once again was that the Collaborative Theory incorporates trust as a theme, denoting the lack of trust may weaken the collaborative strength or productiveness of the team.

Distrust of the Teacher

The teacher was once again pivotal in the parent feeling distrust in the plan and the educational experience. Parent 5 iterated, "I always thought it was, it's just the teacher. You can't blame the whole school district on a bad teacher." Often the safety or wellbeing of the child was at the

center point, and parents felt uncomfortable leaving their child with a teacher they did not feel was trustworthy. Parent 10 outlined a year that was unsuccessful for her student,

I had a teacher where I got bad notes every day. It was the worst year, second grade. 'Student 10 did this; Student 10 did this.' And I thought I was sending my child to school, and he was angry and sad every day, and that was heartbreaking.

All of the parents indicated at least one year in the educational process that was unproductive due to the lack of trust engendered by the teacher. However, the need for a trusting relationship increased in importance as the transition planning came into play. Parents recognized the growing urgency of relevant planning and expressed wanting the teacher to be a trusted partner. Unfortunately, this was not always the case. Parent 6 relayed her frustration in the lack of trust in the knowledge of the high school teachers when it came to understanding the post-secondary supports,

Student 6 had a different teacher every year of his four years in high school. So, I felt like that whole four years was a complete waste, to be honest. I don't feel like they're as knowledgeable. I had a teacher ask me, 'Are you with HCS?' and I said, 'No, we just chose to go with CLASSE,' and she had never even heard of CLASSE... she doesn't know what CLASSE is...crazy.

Besides the understanding of the transition process, parents at times, did not trust the teacher to implement the IEP or provide support accommodations or services needed per the IEP or transition supplement. Parent 5 went as far as checking-up on the teachers,

I got a couple of bad teachers, and one was so bad that every Friday when I was off, I would show up unannounced, and the office would say, 'Ma'am, did you want us to let her know?' And I'm like, 'No. I'm going to watch through and see what's going on.

As the parents began to relate and remember the negative experiences, their body language changed, and the parents became more animated in expressing their words. When talking about these negative episodes, they were not simply isolated incidents that concerned parents. Instead, it was the underlying systemic feeling of unease that parents outlined. Parent 4

related multiple high school years of not receiving reports and losing trust, “When you have a team that erodes at the teacher’s responsibilities or rule, or authority, or whatever you want to call it, it affects everybody.” Parent 4 voiced that the lack of trust occurred in the transition planning years, which “could impact their whole life.”

To combat these feelings, four parents reported the need to have at least one trusted person in the classroom, typically in the form of a paraprofessional aide. “It’s, kind of, we’ll say on the sly, ‘Hey look, they’re not doing this or not following through with this.’” Another parent agreed, “You always have a whistleblower.” The parents also relied on therapists to provide insight on follow-through in the classroom. For example, Parent 12 observed, “You do, you have to...the OT would go to lunch with her once a week and make sure the aides were doing it properly. Perfect.”

Distrust of the Transition Team

Parents cited distrust of the Transition and IEP teams during the IEP meetings. Of the 12 participants, a feeling of an ‘us against them’ atmosphere when attending transition/IEP meetings was unanimous at least at some point in their cumulative experience. Parent 4 suggested, “I think with the school, it was us advocating for him and we felt alone. It was against all of them rather than with them.” Parent 9 claimed that she had only ever once initially agreed with an IEP, “[the teacher] is the only one I have ever signed an IEP day of with...only once. The other people I don’t trust them. I have trust issues.” This quote underlines the power of trust with the teacher. Parent’s degrees of distrust varied; Parent 4 stated significant distrust in the team for most transition years. The distrust centered around being told misinformation by the teacher and the team and then the perception of a cover-up rather than correcting the mistake. In Parent 4’s words,

That is what I have faced. It is a mafia. They're all covering for one another. They all know what their legal rights are, and they all know what is legal and what doesn't have weight. The parent who doesn't know, you're clueless. They're sitting there. Now, I look back on so many of these meetings with so much I have learned, and I feel like a fool from some of the past meetings because I go, 'Oh my God, I didn't even know.' And they all knew. That's the thing. They sit there, and they all knew.

Whereas Parent 7 illustrated a minimal element of distrust in having to fight for services she felt her child needed, but that the result was in the best interest of the child,

Initially, I had to fight to keep her in the extended school year because they were saying there was no need for it. She's not going to regress, and I'm like, 'How could you tell?' I'm not going to wait until she regresses to find out we made the wrong decision.' Since having that struggle, every year, it's like, 'Okay, she's going to the extended school year.' They don't even question it anymore. For some of the services, physical therapy, and all that, I've had to fight for more than what she was getting.

The remaining participant's examples of concern and uncertainty of truthfulness with the team fell somewhere between these two examples. One of the commonalities parents mentioned was differences in the transition team's consideration of services and providing the student with supports the parents felt were necessary, and difference of opinion for necessary transition-based goals. All parents cited the lack of collaboration in what the student with SSN should focus on, specifically regarding transition goals with little to no individualization or collaboration. Parent 4 added,

I think that's where the distrust started for me when you sit in a room, and you see they can't justify logically why a goal should be removed. And I am fighting for a goal because I feel that it's a beneficial goal. And then they resort to quoting stuff that doesn't exist to justify it; we have a problem. You know what I mean?

All three focus groups agreed that in anticipating a challenge or a disagreement within the IEP meeting, the number of IEP team members represented by the school increased. Parent 3's comment simply summed up the parent perceptions, "When things were bad, there were a lot of people in the room," and unfortunately, Parent 4 followed in agreement with, "So I guess things have been pretty bad for me because there's always a lot of people in the room." Rather than a

positive perception, the participation of additional school-based participants reinforced the feelings of “us against them.”

Distrust in the District

Lack of trust or opportunities to collaborate at the district level manifested primarily regarding services or programming. IDEA requires administrative personnel to be present in the IEP meeting to provide funds (IDEA, 2004); it was the area of funding and programs where the parents voiced frustration—receiving the services for students typically manifested as a long process. Parent 2 stated she did receive compensatory services; still, it was a time-consuming event. Parent 5 mentioned, “It’s more about the money instead of the individual.” Parent 12 and Parent 1 voiced agreement, “So I think that they try to walk a fine line to see what they can get away with to save money” and “For me, District’s gotten so big, it’s more about the money instead of the individual.”

Parents expressed concern that the district was perhaps removed from and not in touch with the needs of the individual student, especially the complex supports required for students with SSN. Parent 4 stated that the District misrepresents the transition programming, which she feels does not meet the needs of all students, especially those with SSN,

I think, shame on them. And I think the District ought to be able to do better. It is not okay to say, boast of a program. But it is one size fits all, so you get to boast of it... I think my point with the district and with these programs is everybody wants the accolades, right? But at the end of the day, what it boils down to is you’re affecting the lives of each individual kid. There must be common sense. There must be logic.

Several parents mentioned that the district made decisions that may affect the student and family long term, but the district was not responsible once the student aged out. Parent 8 noted, “The school district can step away, and they’re done, and I’m still sitting there, and I can’t let that happen.” Parent 12 noted that even changing districts, she encountered the same concerns.

However, several parents indicated a resolution to problems after obtaining a lawyer or threatening legal action. Parent 12 shared,

Cause like I said, as soon as you say the word ‘lawyer,’ then the whole tone changes. ‘Cause I did that in [previous district] when she was in early childhood. So I know the whole tone changes as soon as you say ‘lawyer.’ But I do, I feel like I won a victory for her.

It is the success of threatening litigation, which could also prove the feelings of “us against them” and the perception that considering the money was a controlling factor by the district.

Parent 4 addressed this perception from the view of a parent not able to afford legal representation,

They take for granted the parents like us don’t have the money to get an attorney and go to court or take it to due process, and they’re right. We don’t have the time. We don’t have the money, because we have kids like this with all these bills. And they know that, and using that to their advantage is just disgusting. So my experience has been horrible for this population.

In summary, Trust was a focal point of a successful collaborative transition program and, ultimately, the successful outcomes for the student and family. Based on the data gathered, it was reassuring that all parents could articulate opportunities for effective and trusting relationships with the transition team and their students’ teachers. Trust also appeared to be the mitigating factor in these positive collaborations. Trust in the district administration seemed to occur when the team disagreed, or the funding was in question. The district representative was able to mediate the situation. Unfortunately, all parents also related perceptions of distrust with the teacher, team, and district administration. As evidenced through the group discussions, distrust was the primary determinant of the lack of successful collaboration. Of the study participants, six of the 12 had used legal representation or had threatened the use of litigation to reach an agreement in services. One hundred percent of the participants indicated a perceived time that they had had to “fight” for services with the transition IEP.

Programming emerged as Theme 2. The Individual Education Program outlined in IDEA (2004) emphasized the need for high expectations and individualization of supports and services. In the focus groups, both these mandates were reflected in conversations and emerged as subthemes within the Theme of Programming. Reported within the subthemes were the elements parents identified as crucial. Within the Individualization category were (a) transition planning, (b) parent as the expert on the child, and (c) post-secondary planning. Within the Expectations subtheme were (a) high expectations and (b) realistic expectations.

Main Theme 2: Transition Programming

The IEP is a broad and widely encompassing program aimed at legally ensuring the educational rights of individuals with disabilities. Analysis of the focus group transcripts and axial coding revealed the overarching theme of Transition Programming and subthemes illuminated as Expectations and Individualization. Additionally, within the subthemes, specific points of interest surfaced as critical elements within the parents' perceptions in creating an appropriate program for their child. Within individualization, areas of import were (a) transition model, (b) parent as the expert on the child, and (c) post-secondary planning. Within the subtheme of Expectations were the primary elements of (a) high expectations and (b) realistic expectations.

The Transition Programming offered to parents varied little between the three districts represented. Only three parents were familiar with the legal expectation of transition planning before the student's initial transition IEP meeting. These individuals were or had been employed with a school district or involved in special education or secondary grades. None of the parents were approached by the school about transition planning before the official start of the transition

planning as dictated by law. Parent 2 stated that when her child reached the age of 14, she had a difficult time imagining what transition or post-secondary could even look like,

To me, it was just a thing getting checked off in the IEP that you talked about up until really 11th grade for me personally. I had to live in the moment because I couldn't contemplate the future because it was too terrifying. So, I would say there's still a lot more education that I could use and would love to have, but at least I know that it exists. I didn't know that until 10th grade or so.

However, one family (Student 7) had conversations about what their child could do as a job by the classroom teacher in a casual, collaborative discussion. This same family had additional guidance from a friend at church who was a transition specialist in another district. The primary parent concerns were the individualization of the transition model and the expectations of all stakeholders.

Subtheme A: Individualization

Parents indicated the need for transition programming individualized to the interests and skills of their child. Individualization is a required element of the IEP, as indicated by the name "Individual." This same individual component is required in the transition planning and in the services and programming provided as determined by the IEP team (IDEA, 2004). The subtheme of individualization emerged as a critical element throughout all of the focus groups. The parents expressed that the complex needs of their children require an approach that may supersede the supports and programming currently and readily available in the school programming agendas. Individualization aspects of the transition programming included the (a) transition model, (b) parent as expert (c) post-secondary.

Transition Model. While the transition planning as part of the IEP should be individualized based on a student's abilities, interests, and preferences, the transition model discussed among the parents had several common components, including (a) goals, (b) job

training, (c) teaching team, and (d) school placement. Typically, transition evaluations, surveys, or inventories are used to identify ways to individualize transition programming. Transition inventories are surveys used by parents, teachers, and students during transition planning to determine support for post-secondary success, based on student interests and preferences (Turnbull et al., 2016). All parents reported they were given transition inventories to assist in preplanning. All of the focus groups discussed receiving transition inventories that were inappropriate for their child and seemed to be a standard requirement; all parents expressed concern about the standardization of the transition inventories sent home each year. Parent 1 confirmed these perceptions of inventories not individualized to student need or interests,

Every year, they send me ridiculous checklists to fill out for transition planning about what do...I have often felt I do these checklists, and none of that information seems to show up anywhere in the IEP or very, very little of it.

The lack of perceived individualized preplanning translated to the perception of unrealistic post-secondary goals that the transition team proposed, such as becoming a “mechanic,” as reported by parent 10. Parents indicated a one-size-fits-all model implemented that did not meet their child’s unique needs, especially for the student requiring the most significant supports. The transition team was fulfilling mandates rather than tailoring the transition program to their child. Parent 4 ruminated this concept;

And one size fits all, so you get to boast of it. And a lot of the people out there who have more functioning kids will never see what parents like myself go through, unfortunately. It is, so I’m not saying the program doesn’t work for some. But you cannot take that program and fit every special need into that program. Because my son is not going to, you almost have to customize, make each level. So, if it’s more severe, then it should be a different program. Then if it’s moderate, it should be a different program, and so on. But what they were trying to do was take my son and try and convince me that it’s an 18 plus program, it’s for the more severe and going up. It’s a transitional program when truth, and in fact, it wasn’t.

Additionally, all six parents who had participated in 18+ programming discussed the shock of transitioning into an 18+ program. They were unprepared for the sudden change in focus and, in their experience, the lack of communication about changes in program characteristics (e.g., length of the day, different supports, and limited access to general education peers). Parent 2 communicated the concerns of all of the parents who had transitioned to the 18+ programming,

I'm going to say I think that more education in the difference between the 9th to 12th-grade program and the 18 plus program would be really helpful. I think that transition was not super clear. I have some friends that had a really hard time with that.

The continuing education programs were not considered universally negative. Still, the uncertainty of the program expectations and the lack of parental input played a large role in the feeling of having little control over the process. Parent 2 shared that she was told the parent did not have input in the 18+ placement or programming,

I was told that it's like going from third to fourth grade and how you can't request that you want Mrs. Smith instead of Mrs. Jones for homeroom because Mrs. Smith is nicer. This is like placing a kid in a classroom by picking the program for the 18+. So no.

Parent 3 agreed, "Yeah, this is the program. You go in. You get what you get."

The additional analysis of the parent-identified components of the transition model included (a) goals, (b) job training, (c) teaching team (d) school placement and are reported in the following sections.

Goals. Parents observed that appropriate goals, crafted to address their child's individualized critical areas of support, were often lacking or not geared toward operational success. The need for the classroom teachers to address the state academic standards within the IEP left a few parents bewildered. In contrast, others understood the legal mandates but questioned the functionality of the end product, creating an academic goal for the sake of an academic goal. Parent 12 viewed it as unrealistic, stating, "They would try to shove these goals

down your face. It's like, this is not my goal. Let's be realistic." Parent 1 expounded on his reasoning,

I really just don't get it, Student 1 will never be able to do algebra or even know what a number is. I want her to be able to be safe and happy. To communicate. I wanted them to focus on the daily stuff. The group homes want kids that can help take care of themselves, and also, you know the other programs, the day habs and such.

Parents seemed insulted by the standard-based goals as a reminder of what their child could not do. However, parents who worked in education understood a bit more about the reasoning of the goal focus, but indicated the standards could be met in a more practical manner and with a goal tailored for the individual child. Parent 2 worked in a district and shared,

I really pushed for those [academic goals] to be very, very functional. I wanted all of his math to be measurement and money. I wanted all of his reading to be recipes and instructions. He isn't ever going to pick up a book and read it. Fiction reading is not a thing he's going to do. So I really wanted to pull that away. The only time I got pushback was whenever those were the targets of that year. Then, they added symmetry and geometry to math goals because that was the Alt Standardized Test objective for that grade or whatever.

Seeming to reinforce the parent's assertion about the goal's lack of the relation to transition or functionality was evidence that as the standardized testing requirements ended, so did the push for academic standard-based goals. Parent 2 continued,

It was a lot easier once he completed his five standard tests because then nobody cared. And the goals could be exactly what we really wanted. And I could get rid of the science goals, and I could get rid of the social studies goals and really target it down to the social skills and those functional life skills goals.

Parents whose students had the most significant and complex support needs seemed to feel the lack of individualization of the transition goals to a greater extent. Parents 4, 5, 6, 10, and 12, whose children were most dependent on external supports for daily living, toileting, and feeding, discussed having to advocate for necessary skills in goals. Parent 5 communicated the

perceived disconnect between typical student expectations and students with exceptional expectations,

And [school OT] said, ‘So, we’re going to go ahead and remove the goal of drinking from a straw, because Student 5 doesn’t tolerate it.’ I said, ‘Well, my goal is your goal. So you will not remove that.’ I said..., my daughter [sibling] didn’t like math, and didn’t tolerate it. I’m not going to pull her out of math class, so we’re going to keep that goal there.’ It’s just so funny how, if there are extra challenges, some people just assume, ‘No, we can’t do that.’

As a follow-up to confirm parent perceptions of need, the goal was maintained, and the student drank from a straw.

Job Training. Job-skills training was prevalent during transition planning; competitive employment was the primary concern of the school. Parents voiced that these employment opportunities, while desired and hoped for, may not be realistic in the future for their child with SSN. Parent 12 ascertained,

I felt like they were trying to push that on me in [district]. So she can work, and I’m like, what is she going to do? You know what I mean? I felt like they were pushing the work thing, and I’m like, no, I know what she is. I’ve accepted it, let’s move on, kind of thing.

Parent 4 worried, “What [transition planning] means for each child is different. So, for my child, he’s never going to work, but where is he going? Is he just going to go through the school system and then sit at home?” Parents voiced the need to provide opportunities for additional student-specific skills training and goal development as it related to post-secondary environments, rather than the determination of competitive employment. Parents felt that the balance between functional goals, social skill goals, and academic goals for their students with SSN was not calculated to the need of individual students, as Parent 8 voiced:

One of my big concerns is that too much emphasis is placed on supported employment, and not enough emphasis is placed on the global needs of the child, and that’s my big complaint. I’ve super addressed that, but I think that from a huge perspective, that the idea of supported employment, that’s all they’re doing at 18 plus, and they’re failing completely to meet the global needs of the child.

Parents did not feel all job training should be eliminated but rather scaled to the individualized student need. Parent 8 expressed the group's opinion;

Let's look at other things. Let's look at behavior, let's look at other things, or at least let's not make the primary focus [competitive employment]; that doesn't mean we can't consider 'Is this employee building skill?', but maybe that would be 20% instead of 80% [of the focus].

Again, the parent's concern was not on the specific requirement of the law but rather how the law was interpreted, implemented, and individualized for their student.

Teaching Team. Consistency and individualization in programming were concerns in all of the focus groups. Maintaining consistency was a challenge through the transition planning process. The consistency element split into the consistency of the teaching team and the consistency of the class, including the student's physical placement on campus. When there was inconsistency in either of these areas of programming, the parents expressed anxiety and concern. However, much of the parent anxiety stemmed from a lack of parental input and if the current program was successful. If the current program was successful, parents did not understand the need for change.

The teachers and the related service personnel played a large role in the satisfaction of parents. Parent 12 stated, "We had the same PT for years in District, same APE teacher, OT I have for a while. But speech changed every year; this inconsistency drives me crazy. These kids need consistency." Parents felt that the teacher was, as mentioned earlier, an essential factor in student success. Some factors that should be considered include whether the student was doing well, and if the teacher and parent have a collaborative relationship before a move or change of teacher. By the same token, parents expressed concern with different teachers rotating through the programs.

When discussing teachers and classrooms, each focus group commented on first-year teachers; parents had mixed feelings. Ultimately, parents felt that first-year teachers with no prior experience in a developmental classroom might have difficulty acclimating to the population unless they had previous experience with the high-needs population. Parent 5 relayed a conversation she and her husband had in the car on the way to the focus group,

There are pros and cons to this, but I do not agree with a first-time teacher being in a special ed class. And that was something my husband brought up on the way here, and I said, 'I hear what you're saying.' 'Cause I don't think someone brand new just getting a degree should go right into special needs. I think they need to really understand what they're getting into, 'cause I've had a handful of teachers that once they encounter me, they never come back the second year. They stay in teaching, but they get out of special ed. But like I was telling my husband on the way here, I said, 'I hear what you're saying, and I completely agree.' That was always my frustration, and they don't know everything that goes on once the bell rings. Because [previous teacher] came in and was a Rockstar from day one, but she was also that para-professional in the classroom with Student 5. So I guess that was if you're already there, you're already interacting, and then they're gonna go ahead and make that change, that probably makes sense.

Schools. When making instructional or programming changes, for example, moving the students to different classrooms, or the movement of classrooms to different campuses, the parents ruminated on the seeming lack of consideration of the progress of the child. Parent 5 expressed a concern of the majority of parents regarding the change of placement for the population of students with sensory challenges and the need for stability,

Just smooth sailing until he graduated. And then they're like... the principal called me in, and they're like, 'He's going to go to another campus.' And that's kind of like when I was telling my husband; I was coming to this meeting during the transition. He said, 'That is the thing that I think during the transition, when a child is excelling, they're doing good at a campus, regardless of the rezoning, they need to leave a child alone.'

Additionally, parents who had transitioned to the 18+ programming, which encompassed shorter days and different buildings, reported both successes and some inconsistencies and challenges. Ultimately the common factor was the individualization of programming and, once establishing

programming, maintenance of the programming, because in the words of Parent 5, “don’t fix it if it’s not broken....Because you cannot mess with the special needs world.”

Parent as an Expert on the Child. The role of being an expert about their child was evident throughout all of the focus groups. Parents indicated feeling frustrated with the team, including having the perception that the rest of the team downplayed their knowledge in transition planning. Parent 5 revealed her straight-forward manner of communicating her expertise with the group, “I’m like, who’s the parents here? You guys are telling me this is best for Student 5? If anybody, I’m going to know Student 5 best, and so this is how we’re gonna do it.” Parent 12 firmly believes that she provides essential information through her efforts to the team, “Yes, I am. I do the research, and I talk to everybody, I read the goals, I see what she does. I see how she comes home sometimes. That’s how I can tell what we need to work on.”

Interestingly, on the other hand, parents of students with more behavioral concerns reported that they felt the team considered as the expert on behavioral strategies used in educating their child. Parent 2 reported,

I’ve always felt that they valued my contributions because they have always treated me as the expert on my kid. They have always said, what are you doing, or how do you handle when, or what do you think about when he does this or does that or does the other? They’ve always really valued my opinion and have asked advice for different situations for how to handle different behavioral ticks or things he’s doing and how to manage different situations if he gets upset or whatnot. They’ve always treated me as the expert on him. I don’t always feel the expert on him. But they’ve always treated me that way.

Parent 3, whose student demonstrated significant behavioral challenges, concurred that she was viewed as the expert and consulted regarding ways to work with unexpected behaviors,

I’ve felt the same on that because her syndrome is so bizarre sometimes compared to others. They had to come to me. Who else are you going to go to? So again, that’s where I felt like there was a lot of collaboration with teachers so that by the time we got to IEPs, they kind of knew where they were going to go. But yeah, definitely, I got a lot of phone calls over the years and I was never away from a phone.

The more significant the support needs of the child and in areas the teacher was perhaps not comfortable, the teachers and schools solicited the “parent as the expert” advice. However, these feelings shifted when making decisions about the transition program. Parents indicated they were not routinely invited to assist in creating plans specifically related to transition planning. Parents who had participated or were currently participating in the 18+ programming felt their expertise could have contributed to the success of the transition plan. The parents felt, as the expert on their child, their input to the plan would have led to successful individualized implementation. Parent 2 illustrated a work placement that occurred for her child without her input;

He has a new teacher and a new placement at the hospital [work placement], and I have no say in that. Finally, when I did talk to somebody, I said, ‘Did anybody bother to take into account that he has this severe phobia of hospitals?’ And they were like-‘That would have been good information to know.’ I go, ‘If you had asked, I would have told you.’ So I did talk to some people at the district level and found out if we can’t overcome the hospital phobia, if he’s going to scream, ‘No doctors, no hospitals,’ every 10 minutes— We do have the option to change, but right now we’re at the hospital.

Parents were concerned about the sustainability of the transition plans created without their direct input, aligned with the individualization of the transition plans. Parent 3 voiced her concern about the success of the post-secondary program implemented for her child, “it crashed and burned really fast, within two weeks. Within two weeks, we were done. I hate to say I was right, but...” Parents felt if the team utilized their expertise of their child, the plan would be more substantial, individualized, and the chance of success greater, even if the success was not explicitly defined. Parent 9 furthered this discussion and voiced the understanding that parents are aware that regardless of plans implemented, success was not guaranteed, but observed that at least everyone was in it together, as a “we,”

All this stuff. I’ve been waiting and researching and researching and researching, but I think too, it’s a part of nobody knows. Nobody really knows what’s going to happen, and

you've got to kind of make it up as you go, which is crazy stressful and scary. But, I'm of the opinion now, I've just got to keep pushing and see what happens. If it's a hot mess, then it's a hot mess, and we start over again.

Ultimately, parents held tight to the belief the transition plan would be sustainable and more apt to experience success if the parents were consulted and their input considered. When the parents felt they were heard or listened to and acknowledged as an expert regarding their child, the levels of trust with the IEP transition team increased.

Post-Secondary Planning. Parents universally reported confusion regarding post-secondary planning. Within the post-secondary confusion, parents communicated they were not aware through the IEP transition planning of opportunities or funds available for their children. While all parents had signed up and were on the "lists," few understood the process and parameters of the state waiver or subsidy programs. Parent 6 summed up the concerns of parents who had participated in 18+ and those who had aged out, about preplanning and being more proactive in the process,

It just feels like I put him in PPCD yesterday. Now we're finished. So definitely I think the more knowledge you have, we would all feel better, and I hope that more parents really take it seriously when we're giving them that information earlier because it goes by so fast. So fast.

Appropriate Environments. Parents whose children have SSN and were in the final stages of planning reported they struggled to find an appropriate placement for their child. There was little to no individualization when provided information by the school regarding post-secondary environments or options. These concerns applied when determining an appropriate post-secondary environment for their student, be that a day-habilitation or a group/residential home, long-term care, and outside agency participation.

During the interviews and meetings of this study, all parents in each focus group participated in exchanging information about post-secondary options for their children outside of

the formalized focus group interviews and the discussion. Group 1, comprised of parents whose children were either currently participating in the 18+ programming or recently aged out, introduced themselves and immediately began sharing information. Parent 3 introduced her child and was directly asked if the child was in a Day-Hab. A commonality emerged about the length of the waiting lists and the prerequisite skills or abilities which might eliminate the students from consideration for specific post-secondary environments. Parent 2, 3, and 10 discussed the difficulty in finding placement for students with more aggressive behaviors, made additionally more complicated if the child has toileting or self-care needs. As Parent 4 observed, “Well, it’s not just the behavior, but they have you on a waiting list to even view the facility. They seem very, what is the word? I guess because they’re in demand, it’s almost like the nose in the air kind of...” When parents discovered appropriate environments, it was due to the diligence of the parent researching rather than the transition team. Parent 5’s experience was similar to others with little to none of the promised help from the school,

I always want them to know what post-graduation looked like. They made it out to be like, ‘Oh, don’t worry about it, and we’ll help you with it.’ And ‘Student 5 will have those four years after he graduates. If we can find a day hab, and he comes to school half-day, then we can transport them over to the day hab and go half-day, like whatever that looks like, we’ll try to help it be as seamless as possible.’ And that was a complete joke.

Long-Term Care. The population of individuals with SSN and complex health challenges are living longer lives, and as a result, consideration of the long-term care and funding is a must. A conversation between Group 1 participants outlined the reality and fears voiced by all of the parents:

Parent 2: We don’t get to be empty nesters. We have our kids with us forever.

Parent 4: Yeah, exactly, exactly.

Parent 3: Yeah, as I always say, we don’t take care of them until we die. We take care of them until they die.

Parent 4: That's right, that's right. And you hope that they go before you because you don't know who's going to take care, well, at least my son anyway. I don't know who's going to take care of him after. So that's something we live with.

All parents discussed trying to navigate the social security and the state waiver systems, which are supposed to provide monies and services for children and families to alleviate some of these economic fears. However, the challenge of understanding the process created more confusion and anxiety. Parent 6 recalled the difficulty in understanding the differences in programming after age 21,

He was getting music therapy, massage therapy, rec therapy, and we made a decision as a family that we needed private duty nursing. So, that waiver that we sat on a waitlist and finally got [access], we lost. And nobody ever told me that, and making that transition to the adult Medicaid was one of the hardest things I've ever gone through in my entire life.

The unique and complex needs for students with SSN and determining available funding post-secondary was reported as not routinely addressed by the transition team. Parent 6 illustrated that lack of clarity of the system could lead to additional stress,

That [understanding funds ended] to me was one of the most disappointing and heartbreaking, and had I known that as a family, we would have been planning more. 'Okay, we need to be putting more money away for day hab' because now all of that is going to come out of, which we're going to do eventually because we want that for him, and that's what we feel like is important.

The shortage of information provided in transition planning was reinforced as Parent 10 responded, "Nobody's ever brought that up. I've never heard, I've never thought about that." None of the parents were provided any information from the school about post-secondary funding or changes in Social Security after the 21st birthday. The lack of consideration for the individual costs and expenses incurred by children with more extensive costs associated with their disabilities was a concern to many parents. Especially concerning were the limits Social Security imposes. Parent 11 summed it up as,

Yeah, which is kind of unfair, even though she's special needs and needs Medicaid and Social Security. You know what? If she can get a little bit more money and working for someone and a company matches your 401K or something, why can't she? Why can't she have that extra cushion? It's not cheap, and that's the problem. People don't realize that if Student 7 gets sick, that's an expense.

A general lack of understanding of the specific and individual processes of planning for post-secondary life of the individual student surfaced as the main parent concern. Parents saw the lack of attention or preplanning, reflecting the child's and family's post-secondary needs, was a deficit of transition planning and prevalent throughout all groups.

Subtheme B: Expectations

Most parents hold expectations for their children, perhaps going to college, getting a job, and being a productive citizen in society. Parents of children with SSN also have expectations for their children; the specifics of these expectations may manifest differently, but the foundations remain—continued learning, active involvement through employment or community, and high quality of life. Based on parent input, these post-secondary plans deviate from those of the school or the outside agency. Parents reflected that high expectations and realistic expectations, at times, both complemented the transition planning and, at other times, missed the mark. Analysis of the subtheme of expectation revealed the school holding high expectations, and parents typically embraced more realistic expectations in the transition planning.

High Expectations. The theme of expectations highlighted high expectations and realistic expectations. Interestingly, the lines began to blur and merge as the conversations took place, and the participants considered their responses while reacting to others within the groups. High expectations were perhaps the most revelatory realization. Parents acknowledged that often the school held higher expectations for their children than the parents, and the results of the more

rigorous expectations had often surprised them, revealing that their child could do more than they thought. As Parent 6 noted,

I learned over the last couple of years that he could do more than what I probably thought he could, and it makes him happy. Especially, I noticed over ... now that we're both home stuck here and he's being in the kitchen with me and doing laundry and doing things that I just ... in normal life, they told me he could do those and I would try once and just gave up. And I realize that it makes him feel good and that's just all I've ever wanted for him, was to always be happy and never feel frustrated or lonely or sad because of everything he's got going on.

Parent 2 explained that perhaps seeing the child through a parent's eyes and based on previous behaviors can limit expectations, and it takes the school's high expectations to reveal the child's abilities;

Yeah, so his independent living skills have really blossomed because if you'd have asked me like three years ago, I would have laughed at the idea of ever leaving him home alone for any period of time. But right now, we're practicing to where he can do the mornings by himself. So, who knows?

Most parents credited the teacher for maintaining high expectations and felt it was dependent on the teacher to maintain high expectations and follow-through. Parent 4 expanded on the importance of the teacher supporting high expectations, as in Parent 4's experience, it was due to the high expectations in middle school that the foundational skills were still present:

[Teacher] pushed him to do stuff that I didn't know he could do. She got him to do stuff that, to this day, those strengths exist. They may not be as strong as they were before. He's also older, and his frame is different. But a lot of what he has built on has been with her, a lot of the foundational stuff. So part of that, to me, I believe that she saw that in him, that she knew he could do it and she stuck it out, and she pushed him. She got him to perform and to do it.

Unfortunately for students with the most SSN, holding the high expectations depended upon the teacher in the classroom. According to Parent 4, the high expectations were not maintained by all teachers. Similarly, Parent 3 expressed appreciation with the school's attempts to obtain the expectations set, even if the results could not be maintained in authentic environments,

I really didn't think she would be able to go to work; I just think the program was good in its expectations for her and its attempts to try to get her to that place. They did a really great job trying. I thought we were going to get there. You know what I mean? Which is something I never thought I would think, and they had me thinking that for a while, so yeah.

The high expectations presented and taught by the school allowed the parents to view their students outside of the lens of parent/child and recognize some additional possibilities. The unsustainability of the skill sets developed in the school environments led to the concerns communicated by all parents that while high, the expectations may not be individualized and maintainable to meet post-secondary needs in areas of independent living, continued education, and employment or community involvement.

Realistic. Parents voiced that the high expectations were appreciated. Still, they were also concerned about the appropriateness of the goals as applied to their students with the most significant and complex support needs. It is vital to meet the dictates of federal law—employment planning—while maintaining the individualized aspect of the student's needs. Parent 10 stated, "The law I think is where that intersects. The law says, "We need to look at this," and I know that from my Special Ed background." Parent 10 also shared the problem,

One year, they told me he wanted to be a mechanic because he picked up a picture of a car. Well, good luck with that. I mean, it's things like that that are kind of ridiculous. I appreciate the attempt, but that doesn't mean he was interested in cars. Who knows? It was in his way, or it was the first one he saw. So, I think it's kind of... it's another professional you go to, and they have opinions about your child that aren't realistic. I know we all want to 'yay yay' this kid. We want them to go as far as they can, and I do; I want Student 10 to go as far as he can, but frankly, Student 10 beat the hell out of me this morning, and unless we can get that under control...and then there's the diaper...so yeah.

The concern about the push for employment was evident with all parents. Parents wanted their children to be active members of society and felt that goals that address social norms, behaviors, and communications might be more critical than specific job skill training. Parent 8 stated,

We're staring at a 13th year in the classroom just because we've got to work on some other issues before we... and we need to gain some ground there before we touch employment. My concern is we could really ... I could lose my child with a focus on employment... So, I think what I'd really love to see is a more level approach, and really look at the child. What do we need to work on? Is it important? Is it really that we need to work on management of behavior and their ability to ... yoga breathing techniques, this kind of thing. Do we need to look at teaching them how to calm themselves before we ever touch that? I think that's where there's a disconnect.

Parents felt like they are conscious of their child's limitations and would be the caregiver after school is over. The data indicated the stress parents feel, trying to hold high expectations and yet at the same time trying to prepare for the future with no illusions, as Parent 7 shared,

I hate to say, but I'm not horribly optimistic about Student 7 being employed when she finishes high school. I hope she can find some kind of a program where she can go every day, where she can have a place to go, something to look forward to, a way to interact with other people. I love her, and I don't mean to be negative about my own child, but I don't think she has a lot of sustainable skills that she's going to be able to maintain employment without somebody constantly being on top of her. So, I mean I'm just kind of, I guess, taking a wait-and-see attitude.

Ultimately, parents felt that the high expectations of the school were valuable and appreciated but voiced the concern of continuity, support, and maintenance needed in post-secondary environments to maintain the skills; that without the continued specialized support schools provided, the skills were not maintained long-term or generalized post-secondary. As Parent 3 stated, "But yeah, they did a great job with her job training. It's just, and it didn't then apply to the real world. So, it crashed and burned."

Category 2: Role of Parent

The parent is a vital and required member of the IEP team and, therefore, of the transition planning team (IDEA, 2004). IDEA is clear in its determination of parent participation on the team "(a) General. The public agency must ensure that the IEP Team for each child with a disability includes—(1) The parents of the child." However, not provided is a description of the roles and responsibilities of the parent within federal law. Under Category Two: Parent Role,

specific themes emerged within the focus groups as the parents discussed their perceptions. The parents regarded their role as twofold: (a) as an advocate, and (b) as a member of the IEP team. Discussions outlined the times these roles became singular and collaborative, and when the parent felt the separateness of the roles. The following explores the theme of advocate and subthemes (a) advocate for own child and (b) advocate for others. The second theme of the IEP team revealed and discussed was IEP member and the subthemes of (a) parent IEP member and (b) other IEP members.

Main Theme 3: Advocacy

The theme of advocacy emerged as a driving impetus of the overarching role of the parent. Interestingly, while advocacy of their child was not surprising, the parents also indicated the need to advocate for other children and parents through their efforts. While advocacy for others may be a byproduct of personal advocacy, it was revealed that parents were very conscious of advocating for others through their efforts.

Subtheme A: Advocate for Child

All parents viewed their primary role in transition planning as an advocate for their child. Echoes of the “us against them” mentality and the need to fight for perceived services were present as parents discussed the constant need to advocate throughout the transition process. The intensity of the advocacy varied and was mostly dependent on the reaction of the team or school (as an entity). Often, the advocacy was a consistent push for “better” and to think outside of the box in developing an individualized program, at times challenging the propositions of the school-based IEP team. Parent 9 related how advocacy helped her and her child move forward:

I think I was bossy cow. I've always been the bossy cow in the IEPs. I always steered the ship. I think I've always been super clear on what I want for him and where I want him to go, ...just being that pushy parent in middle school and high school. Like, 'Nope, we're going to try this,' and [a specific teacher] was always on board. I'm like, 'Okay! Let's do it' ...That's how we did it, forged ahead.

All parents felt that it was a struggle and unpleasant at some point in their child's educational career, and perhaps more so in transition planning. Illustrated were the moments of perceived struggles, as Parent 5 related the need for a stronger tone to address the team. In a possible disagreement, the parent was forced to make an unwavering stand to proposals:

It's almost like you have to become a spawn of Satan for people to listen. Because if you're just very, well, you can hold your composure, yourself together. And they're like, 'Yeah, no.' And then you just blow up, and you're like, okay, we'll just stop this meeting, and when you all want to act right, we'll come back, and I'm the one that's not acting right. But you have to almost act just crazy to get their attention, to finally understand that you're serious. And it's not about us. ...this is all for a child and an education, whether you think they're learning or not. But regardless of the level of how they comprehend, it's still a sponge. And if it doesn't happen today, they're going to pick that up sometime, and you're going to see it. And so that is just where I'm like, I'll advocate, I'll fight you every single day, but I shouldn't have to.

Underlining, at times, the unpleasantness of the role of advocacy was the aspect of isolation. All parents indicated they had felt alone at least once in the transition process while advocating for their child. Parent 4 explained what the majority of parents communicated, perceptions of the solitary process:

I know I'm part of the transition team because I have lived that over the years and become the advocate for him. I recognize that they are supposed to allow me to help make those decisions, but I think in us advocating for him, we felt alone. It was against all of them rather than with them.

However, the advocacy for children was worth the fight and the stress, as most parents received the services for which they advocated. Through the struggles, parents acknowledged that advocating for the child can be advantageous; it was seen as a means to a necessary end.

Parent 12 provided insight that positive outcomes because of her advocacy were a success in the interest of the child:

But I do, I feel like it's like a victory. It's just getting the stuff that she needs anyway, and they just don't want to pay for it, and then I have to fight for it. So at the end, I feel like I'm vindicated. Like they tried to argue with me that this isn't what she needed, and I stood my ground—getting what I want for my daughter. I do, I feel like I wanna come out of there and be like Rocky. Like, I did it, I did it. I got everything she needs. I do, I feel like I had to, I do.

Parents recognized that the school provided positive advocacy for their child through individual school personnel and the High Expectations mentioned previously. Parent 1 noted that the school advocated for the correct services for his child, “I wish I had listened to them in the beginning, especially the in-home-parent trainer, I just thought I knew best, you know I was like her parent.” Parent 12 stated, “the flip side of that, I've had some [school personnel] that will say, “I'm so thankful that you're involved. We don't get a lot of parents that are involved.” Parent 8 stated, “I think that the people who do go in, and they are more really looking and really want something for their child. They [school personnel] may like it or not, but I know they respect those parents.”

Ultimately, parents viewed their primary role throughout the transition planning and educational services as an unwavering advocate for their child and used the term “fight” universally as an advocacy tool. All parents indicated a desire to have and have had a positive experience partnering with a school representative in advocating on the part of the student. But, while elements of the schools may support their student, ultimately, the one fully invested was the parent. Parent 5 summed up the primary goal of membership in the transition planning team,

Me just being an advocate for my son, because nobody else will. If it wasn't for me showing up and being the eyes, the ears, the voice for him, that is very rewarding going in there. Yeah, I want my voice to be heard, but at the end of the day, it's what's gonna be best for him and getting what is gonna be best for him.

Subtheme B: Advocate for Others

The participants' role of advocacy extended to the obligation to advocate for others. The parents realized their push for supports, services, and programming was inclusive of advocating for families and students beyond their own. This understanding was a conscious revelation of the participants of this study. Throughout the focus groups and unprompted, the parents included others in examining their roles on the Transition Team. Parent 12 explained the opportunities she has had to educate other parents going through similar experiences:

I said, 'You could fight for students.' She goes, "I can?" And I'm like, 'Oh yeah, you can. You can fight for anything.' That's where the parents, all the parents just don't know. You can fight for anything. 'Oh, okay.' Because they don't know what their rights are. They don't realize. ... There's a lot of parents that don't. They don't go to the IEPs. They just take whatever the school gives them. I feel like I have to speak for them.

Parents voiced a realization that their advocacy may not be the norm, but that their advocacy was necessary. Parent 5 expressed the passion and fortitude behind the advocacy for others through advocacy for their child,

I also think what it is... there's not a lot of parents that fight for other children in our situation... and so the couple of us that show up, we have so much anger for all of 'em. So we're just busting through the doors, and we're getting a lot of 'No's.' We're trying to advocate for our own child, and they're [school] like, 'Oh, this is just a one-off.' And it's not.

Parents communicated concern regarding the abilities of other parents to advocate for their children. Advocacy entailed a lot of work and resources as voiced by Parent 4. "I've been doing so many of these, these IEPs, but my point is if I only found that out this year, what about the parents who did not advocate or who are not taking the time to educate themselves?" Therefore, the more active parent participants felt a responsibility to be the voice of all children with SSN. Parent 5 noted that parents did need to be a proactive participant in discussing the difference in her and other's advocacy,

But you kinda have to take it upon yourself to go to these parent meetings and talk to people and get on some of these websites and Facebook pages and be more active in your approach. I feel bad for her [another parent] daughter because she's the one that's gonna suffer. She can't speak for herself either.

Additionally, parents voiced the understanding that the supports they pushed for could impact the greater population. Parent 12 reported, "I kept trying to include all the other kids in the classroom for a sensory area. We set up this whole sensory area in the classroom, and it made the difference for all the kids. I kept trying to fight for this because I have to be the voice." And Parent 11 stated, "Oh yeah. Yeah. Hopefully, we make it easier for people coming in now through the district thing." Ultimately, Parent 5 voiced the prevalent feeling regarding advocacy for others: "I think I have a very active role. I think I wish more parents would have some role. I think you either have like us at the top, or you have just people who don't come at all."

Main Theme 4: IEP Roles

IDEA (2004) asserts individual members are required at a transition IEP meeting. This law included all members of a general IEP meeting with the addition of the child with disabilities, an outside agency representative (with parent consent), and while transition specialists are not a required member of the transition IEP, if invited by the parent or an employee of the district may participate. Throughout the interviews and as stated in the previously reported themes, parents, while knowing they are team members, viewed their membership differently than the school-based members. Investigation of the parent perception of roles led to the breakdown of how (a) how other members viewed parents and (b) how parents viewed other team members.

Subtheme A: Members Viewed Parents' Roles

How other team members viewed the parent's role in the planning process surfaced as a subtheme in the general team member roles. Parents felt the other team members respected them

as a whole, but they did not consistently feel treated as an equal member of the IEP transition team. Parents acknowledged feeling the other team members would be happier with automatic compliance and agreement. The term bossy was said on more than one occasion by parents, as Parent 10 stated, “I mean, I’m pretty bossy. I think we’ve all said that, so I think they respect me because they know I’m going to... I’ve not signed an IEP before as an educator. I’ve said, “I’m not signing that.” Parent 8 agreed, “I think they’d love us just to sign and go. I mean, they would love that...” Parent 5 joked the other members of the team perceived her as “Mental issues. Unstable.” Parent 4 felt the other team members viewed her as “an inconvenience because I had educated myself on the process. So, I became a problem, that’s what it is, because now I know the system to a large extent, not entirely.”

While all parents reported having disagreements and advocating for their children could be isolating and difficult, all but one of the parents said they felt respected. Their input was valued most of the time. Parent 12 summed up the group’s majority consensus,

I think they’re happy I take an active role, but I know sometimes I don’t think they’re prepared for some of the things that I want. You know what I’m saying? I think they’re happy that I have an active role in Student 12’s, but I think I can overwhelm the whole conversation, I think.

It was interesting to note that parents discussed how their role was viewed and responded to in terms of “respected” and “listened to,” but only after establishing themselves as advocates for their child. This brings to light the point that parents viewed being respected and valued in conjunction with how others viewed their role on the team. Parent 4 made an interesting observation and one that underlined the active involvement of parents as team members and advocates,

I think that I am supposed to be part of the IEP team. I made myself part of the IEP team because it affects my son. So, unless you have a personality like mine, as I’m sure everybody here has that personality because we’ve had to fight, I’m sure, for everything.

So unless you are that person who knows that you're part of the IEP team, then you're not really part of the IEP team.

Subtheme B: Parent Viewed Member Roles

The parent's understanding of the roles and responsibilities of all transition and IEP team members proved to be an area of uncertainty and, perhaps, one of the most perplexing components of the team. Parent 2 iterated one of the barriers to transition that reflected the views of the parents not directly involved in special education, "Not understanding the roles of all the people involved, like specifically." The roles of the team were divided into (a) school-based personnel and (b) outside agency/VR members.

School-Based Team Members. The transition specialist was unknown to some parents. Parent 1 professed to be unaware of the position or what their role was, "I have never met them, and so what do they do? I mean, it sounds like they would have been very helpful, are they supposed to be there? Gosh, I just don't know." A small number of parents (two) were aware of the transition specialist in their district and had direct encounters. However, both cases resulted in different outcomes, as Parent 12 and Parent 5 respectively discussed. Parent 12 had a very positive relationship:

Trans Spec. is wonderful with the resources. She really is. I mean, she's better than what I had in the previous district... she's one of a kind, she knows Student 12, she observed her in the classroom for... I went there at 15yrs, so she starts transition stuff there. But again, it's not what everything you're looking for, but she does, I think she's better than most, and I like that she gets to know that the kids because when we spoke at a parent panel, there were some parents from District and they're also... And the fact that Trans Spec. knew all the kids, that's what I loved about her.

However, Parent 5 had an unproductive interaction and felt it was just a logistical requirement:

I know the closer Student 5 got to it [IEP meeting], I would get her phone call, 'Hey. I'm just checking on you. Student 5's getting close. I just didn't know what the goal was.' I thought, 'Why are you calling me just to see what kind of work that I've done towards getting Student 5 all set up when that should have been your job?' I didn't understand her role.

A review of the roles of the other required members resulted in a similar inconsistency. Most parents did not feel the principal or the campus administrator played a significant role on the team. However, the two parents who reported participation by a principal viewed the results differently. Parent 4 outlined her respect for the campus administrator, “I mean, Principal was a dream, in my opinion. That’s my encounter with the man, right? With the team and with just everything that we dealt with at Middle School.” Whereas Parent 12 held a less than flattering perspective,

I mean, I don’t like the principal at District High School or the assistant principal, but I feel like they don’t have enough. They don’t really have a lot to do with her unless... So I feel like I get more if I go over their heads, which I have no problem doing. So I feel I get the support from the district, I guess, from Sped Admin.

Interestingly the general education teacher, a required member, was only mentioned one time, and it was in the role of an elective teacher but was very supportive of the Parent 12’s involvement,

Her floral design teacher says that to me. She goes, “I only had to go to a few of these, at least you show up. You have questions. You get involved.” She goes, “You’re very passionate.” I said, “I am. That’s my daughter.”

Ultimately, the question of other team members’ roles was met with trepidation and uncertainty when viewed singularly; instead, the transition IEP team, except for the case manager, seemed to be considered a group. Parents’ responses revealed a lack of clarity of the specific roles and responsibilities of the other team members and that these positions had not been the focus during the transition planning processes.

Outside Agency and Vocational Representatives. Parents universally conveyed not understanding the role of the outside agency as an IEP member, as reflected by Parent 2’s statement, “I still don’t really know all the things that State Workforce Commission is supposed

to be able to.” Only two parents reported the agency representative attending the IEP meeting, though a majority of parents indicated the representative had been invited. Parents 2 and 3, respectively, recalled the invited interagency representatives’ lack of attendance and their unresponsive role in the transition team to provide individualized services for the student; per Parent 2,

With the transition, oh, I know. Whenever you check the permission for all those people to show up at the IEP- they never show. Yeah, sure. I’m like, ‘Yeah, invite the world. I don’t care,’ but no, because none of them are ever going to go. I’ve had State Workforce come, but that was because she needed to talk to me.

Parent 3 immediately concurred, “Yeah, they never came.” No parent reported outside agencies working directly with the transition team. Instead, parents agreed that trying to contact the needed vocational supports was often a disappointing process. In her first experience with the transition team, Parent 7 reported she attempted to make contact, but...

I asked, ‘is somebody from the State employment going to be there to kind of give us guidelines as what options are even available for Student 7?’ We were told no, it’s too early in the process to think about that. I’m like, ‘Well, that’s what I want to know about.’ So, I guess I’m just kind of waiting to see what’s available to me.

However, there were exceptions, and these exceptions were driven by the parent contacting a specific person at an agency. These parent-initiated contacts resulted in collaboration and positive outcomes. Parent 5 discussed the need to keep trying and ultimately succeeding in the quest to connect with a representative. Parent 4 discussed having a very productive relationship with the outside agency representative working with her son:

They have been amazing. I have nothing but good things to say about them. They’ve been incredible, and they have supported big-time, meaning if I need information on something, they will try to get that information. We work it out together. His person or whatever they call has been amazing, just amazing. So that’s been a big point of resource, a big resource for us, but then also calling... That’s what it is. It’s not from the district. It should be. It should be that transition team. It should be the group.

Parent 4 and Parent 5 had developed relationships with the outside agency that has been their support. The agency representative has provided resources as well as guidance in navigating post-secondary environments. But the direct connection with the vocational agency did not come from individualization or collaboration of the transition team planning, but rather from the parent developing a relationship with the agency personnel. It was important to note this was only the case for two parents. The other parents did not report anything similar.

In summary, the individualization happened if the parents had a positive collaboration with the teacher and the transition team. Per the data gathered, it appeared the parent was the driving investigator and implementer in the individualization of post-secondary environments.

Category 3: Self-Efficacy

Self-Efficacy is the personal perception of ones ability to accomplish tasks or be proficient in an endeavor, how well a person believes they can do something, and intimate knowledge of a topic. “Self-efficacy beliefs determine how people feel, think, motivate themselves, and behave” (Bandura, p. 72, 1994). The final category explored in this inquiry was the method and process of building parent self-efficacy through their lived experiences of participating in the planning of their student’s transition into post-secondary environments. During the discussions within the focus groups, a common theme related to personal self-efficacy linked explicitly to transition development. This theme was Time and Toll.

Further analysis revealed two subthemes: (a) personal and (b) resources. The time and toll reflected parent efforts in developing expertise and capacity in the transition planning process. Parents additionally commented on self-efficacy outcomes. Parents discussed whether the increase in their self-efficacy or if receiving resources earlier would have improved collaborative processes.

Main Theme 5: Time and Toll

Parents felt that the burden of increasing their self-efficacy in transition planning could be an overwhelming process. Multiple layers constituted the time and toll experienced by parents of children transitioning into post-secondary environments and future planning. These layers of time and toll included uncertainty of their research, time the research took, the unknown of the future, and the complex needs of their child. These reported stressors were compounded by the mental and emotional toll of guilt the parents felt about the effects on families. Parent conversations revealed the layers of gathering knowledge and accumulating resources could be measured through negative effects that included physical and emotional toll.

Subtheme A: Personal

Physically, parents reported the time it takes to research and discover the appropriate resources for their student with SSN was equivalent to another job. Parent 2 observed,

I think that transition is a lot more challenging whenever there's not a parent that can actually dedicate almost a full-time job to handling it... variation and things like that, just because there's only so much things I can juggle at once and only so many things I can do at once. So whenever he's out of school, I have to pay a sitter to stay with him all day. I mean, I can't afford to take him places or whatever, if they can't get the government to help basically.

Parent 11 reported stress, even in the first year of transition planning, "I've spent time looking, but it's overwhelming. I'm not sure if I'm in the right area and stuff, and then you have to fill out all this stuff." Parent 6 provided additional content regarding the time to connect with agencies, illustrating the feeling that others do not understand the stress related to the transition process,

I was thinking it's lonely and isolating, too. Because nobody understands. Nobody understands. I remember when I was going through all that last summer, it was so awful. I don't ask for help very well. And the other feeling, when y'all were talking, my best friend was here spending the afternoon, and I got a phone call from somebody, I don't know who it was from, somebody down in State agency. I had it on speaker on my phone, and it was one of the most frustrating conversations, it was around and around. It was just ridiculous. And I got off the phone, and she was like, 'I cannot believe that that

just happened.’ I think when I explained it to her, she was probably just like, ‘Oh yeah, it’s hard.’ But when I got off that phone call, she was like, ‘if you have to have phone calls like that all the time, I just can’t believe you have to go through that.’ So, nobody understands, and it makes you feel lonely and isolated. That’s it.

All parents communicated that the stress was not just related to the amount of time the process takes but also to the emotional toll and the feelings of guilt parents experienced. Parent 10 illustrated these emotions,

It’s exhausting. I never know, am I making the right decision today that’s going to be good tomorrow? Or what about in 10 years? It’s a what if? What if, what if, what if? And you have to plan for every single scenario, and your brain never gets to shut off. You start to go, “Okay, we got this,” and then someone says, when are you doing guardianship paperwork?

Within the family, the emotional toll and guilt are not limited to the child with SSN. The parents also worry about slighting the other members of the family and not meeting everyone’s needs.

Parent 7 shared their concern,

You want to make sure your typical children are getting normal life experiences. Because really, if it were up to just me and Student 7’s, we’d just hang out and do nothing. But I want siblings to have a normal experience and to get to travel. And he’s older now, and he wants to take trips and go places, and I’m like, “But your sister doesn’t travel well.” It’s a struggle.

Parents all emphasized adding to the additional mental toll was the constant uncertainty of whether the preplanning and the desire to balance all elements of providing a “normal” experience for the child and the family will work out. Parents explained that even with all the planning they do to ensure that the child participates as typically as possible, things often go awry. Parent 9 recounted how often the efforts did not turn out as planned,

It’s hard. I want him to go. This was a couple of years ago, and it was for his brother’s birthday. I’m like, ‘I want Student 9 to go. Both his brothers are going, it’s going to be awesome, great family trip.’ It was a disaster. It was a disaster. I had to give him a piggyback in my bikini on the hot pavement everywhere, and he just melted down and shut down and his dad’s like ‘See? I told you this was too much for him.’ And I’m like, ‘But I want him to have that opportunity.’ And again, that was a hot mess, but still, I have that guilt. I don’t know how to ...

Compounding the guilt and the feelings of having to provide for everyone's needs was their struggle with asking for help from friends, family members, or spouses. As Parent 10 said, "Even if it wasn't the guilt of just your child, some of the guilt was in asking for help." Others concurred asking for personal help was hard. Besides the personal toll, parents expressed that one of the greatest challenges to transition planning was the time it takes to gather transition resources.

Subtheme B: Resources

Parents reported they received information from three primary sources, schools, the internet, and friends/support groups. However, the amount, quality, and satisfaction of information varied between sources. Participants between and within focus groups indicated similar experiences in building transition self-efficacy.

School. Receiving specific assistance and information related to a successful transition into post-secondary environments from the school was a disappointing experience for most parents. The exception being one family whose child has just begun the transition planning process. When I asked how the school provided resources, the single word answer from several parents was "the packet" received from schools in the transition IEP. The school, in the experience of Parents 11 of the 12, gave the parents generic transition packets containing information regarding transition for all levels of students. The helpfulness of this packet was debatable as parents mentioned the frustration that the packets provided links and internet resources, but that the links were often out of date or broken and did not lead to success. An interesting exchange within Focus Group 2 illustrated the inconsistency of receiving resources from the schools. When the packet was mentioned, Parent 8 exclaimed, "I don't know what you're talking about." Parent 10 pulled up an email and passed it to Parent 8, and Parent 8

expressed her thanks. The exchange was not only an example of the lack of resources provided, but it also illustrated the collaboration and support parents received from each other. Parent 10 replied, “Well, for us, when Student 10 started, there was no packet.” Parent 7 commented they had not read the “packet” until recently. But Parent 4 made perhaps the most powerful statement, that she felt the “packet” might have taken the place of the transition team for her,

Also, the transition team, it’s null and void. It was a packet. They hand you the same thing every year. That’s the transition packet, but I did not know- all of the numbers, a ton of them that’s not even valid or whatever right now, but it’s the same packet that they’ve been using for years. Yeah, it’s not even updated or whatever, but in addition, the IEP committee, which also has a transition team, I didn’t know they were a transition team. The transition team was the packet.

Other parents concurred that the district emphasized the transition packet, rather than direct training or being provided with specific helpful resources. Parent 10 added a possible reason the school relied heavily on the packet of information,

I don’t feel like they’re [teachers] as knowledgeable. I think they know about the State Workforce Commission. I think they know about those things. But I don’t think most high school teachers know about the down and dirty. That’s been my experience, at least. It’s like the harder the kid is, the less they know. Which I get it, but still.

Parents did receive perfunctory information during the IEP team meeting, information that was required by law. Parent 1 recalled receiving some transition information at the IEP meeting:

Yeah, the diag. [diagnostician] talked about guardianship and getting that, but nothing about how or who to make it happen, that was on us, a lot and confusing and cost us. I think more information would have been appreciated but put it on our radar.

However, several parents had attended training by a local financial provider that the schools provided information on for post-secondary planning. Parent 6 attended, “I went to some workshops through the Down Syndrome Guild.” Some parents had difficulty remembering if the information came from school or through their research. According to parents, the district does not assist with finding post-secondary environments for students with SSN. This information

confirmed the perspective of all of the parents who had participated in 18+ programming. Parent 12 related what she was told, “They said, ‘You’re going to have to find a day hab for her...because District doesn’t do this.’ I’m like, ‘well, no, you were supposed to meet once a week.’ I got it.” School-provided resources that were helpful seemed to come from individuals, teachers, case managers, and specific campus staff. Parent 9 relayed, “The [teacher and instructional coach] gave us most of the information. Parent 12 recalled a parent panel in her district organized by the transition specialist:

My transition specialist for District is a lot better. So, I’ve actually spoken on a few of her parent panels because there’s a lot of people coming into this area who don’t know that they need to get their kids on these lists, who don’t know anything about [transition]. They didn’t know they had to get guardianship of their children at 18, or depending on the disability, like my daughter, you know? But I mean, I spoke on a few of these things for her. So it was a good resource for all the parents to meet because it’s different stages, some of them were in elementary, some were in the middle. We had two of us in high school, one and then there were two parents’ post-secondary on this panel for all these other parents, but it was great to get to know.

Based on the focus groups’ conversations, the information provided by the school was not universally individualized for the child. As Parent 8 pointed out, “I’ve gotten nothing but incomplete information and just not a lot from the district.” The most helpful resources provided through the schools were instigated by individuals rather than by the school district as a whole, and not provided for all transitioning students or families, but the recipients appreciated provided resources.

Internet. Parents often reported relying on the internet for information to provide answers. In each focus group, the single word reply was “internet.” Parent 5 expounded on using the internet to find post-secondary environments appropriate for their son,

So I looked at the packet, but I also Googled a lot to see what others out there. Because I’ve hit every single day-hab in the area. Whereas I can’t give credit because I was the one going, day hab hopping, Googling.

Parent 12 agreed that her initial go-to was the internet:

[At] 14 when they said to start looking at what you want for postgraduate to be like. So, I started it, and that's when I really started Googling it and looking into things or talking to parents. Googling everything."

Although parents relied heavily on the internet, they did question the reliability of the information they found online. Parent 11, for example, mentioned, "even if you go online, you can't find anything. There's a lot of misinformation, and it's a lot of vague stuff." When speaking of the internet, parents typically linked the Facebook groups and support groups, which emerged as the next area of support.

Friends/Support Groups. Undoubtedly, networking and information obtained from other parents and support groups were the go-to for guidance for all parents who participated in the study. I recognized networking occurred between all of the participants in each focus group throughout the meeting—beginning, middle, and end. Parent 3 even pointed out the fact, "But see how you just saw this in action? I just got some information from another parent."

Parents indicated an implicit trust in parents who had experienced what they are experiencing and learning from their successes and failures. Parent 10 described, "But it was parents that I talked to that I'm like, 'Okay really, what are y'all doing with your kids?'" Parent 7 continued with a trusted friend,

I had the advantage of somebody who went to our church...was very active in the Transition program, so she already introduced more than anyone in the school district just in casual conversations. I got more information from her, I think.

Parent 4 offered, "One person gives you a number. 'Oh, you know who would have great information?' and I call. So, it's a chain really, and that's how it's gone along." Parent 12 outlined, "There are many Facebook groups. There are Special Needs Parents of North State, and then there's a bunch of Facebook groups that I learned a lot on."

However, even with the mutual supports and sharing of information, there remained the underlying concerns about having enough or the right information. Parent 8 reiterated, “That’s been helpful, and then I’m still always worried I’m still missing something.” The fears and uncertainty that parents were not equipped to ensure the security of their children’s post-secondary environments were consistent with Theme 4: Time and Toll.

Self-Efficacy Outcomes. Parents reported mixed feelings on their self-efficacy. As an aspect of time and toll, parents felt sometimes they could accomplish anything, and other times they thought they had missed something. But overall, the parents reported that they felt more confident as their knowledge and experience increased. Parent 6 illustrated these feelings,

Oh my gosh, I fluctuate between feeling like I’ve got ahold of what’s going on and then like y’all said, suddenly it’s like, “What? I have to choose? I have to get rid of my waiver?” Now that we’re through it, Student 6’s done with District, we’re done, no more IEPs. Now that we’re through it, I feel like I can kind of relax a little bit. But I feel okay.

Interestingly, the IEP process may have increased the stress of transition planning. Still, the actual learning and researching of transition planning through various methods may have increased the overall feelings of ability. As Parent 9 reported, her personal learning about transition decreased her anxiety and increased her confidence:

But I think just doing a lot of my own research and finding out ... like I attended a Zoom for Local Day-Hab the other day. It was very enlightening, very interesting, just out there searching and seeing- I feel better than I did. I’m not so panicky.

Parents indicated that when they accomplished a task or worked their way through the post-secondary services or funding, they felt better. Parent 10 stated,

I feel fairly confident. I feel like my confidence has certainly grown. I remember thinking, “I don’t even know where we’re at.” But it’s also like a maze that you’re walking through and you just keep going because you know there’s the end somewhere, but you don’t know what’s coming around the corner.

However, Parents 7 and 11 were just beginning the transition process, not yet exposed to resources or having had more than one meeting, still reported apprehension, and perhaps the unknown was a precipitator of Parent 7's anxiety,

I mean, as far as where I am in the process, I'm feeling pretty terrified and overwhelmed right now. Because I don't know what to expect and I really don't know what the future holds for Student 7, what's out there for her. So I hope in a year or two down the line I'll be where you are and feel better about it, but right now, I'm pretty freaked out.

When asked if given additional transition resources earlier in the process, if the transition team collaboration would have increased, both Parent 5 and Parent 12 replied in the negative. Parent 5 stated, "No, I don't think so... It would have been nice to get more help." Parent 12 said, "Not for me, no... So, I mean, I've done most of the work..." Both parents also indicated that they could not give credit to another when they had done all of the work.

However, eight other parents felt that additional resources and beginning sooner would have increased their levels of self-efficacy and collaboration in the process. Parent 9 commented, "I do, I don't think it would've been as much of a fight. Or I don't know that fight; sometimes fight was the word. But sometimes, the fight is not the word. Pushing that rock up- by yourself." Parent 6 added,

I think yes, definitely if I'd known earlier. I think that's impacted now that I work at the school, we give the waitlist to parents when their kids are turning three, and they look at us like we're nuts. But I was them yesterday. It just feels like I put him in PPCD yesterday. Now we're finished. So definitely, I think the more knowledge you have, we would all feel better, and I hope that more parents really take it seriously when we're giving them that information earlier because it goes by so fast. So fast.

In summary, parents felt there were always new things to learn or something they did not know, and they were in a state of uncertainty and imbalance; as Parent 3 described it, "I just still feel like that's just a gray world out there until we get to it, because who knows what it will be?" While the knowledge and feelings of self-efficacy have increased throughout the process of

transition, sustained team collaboration was inconsistent. The transition process continues to be a singular journey and one that the outcomes are currently unknown. As Parent 2 reflected,

I don't feel like that the world is prepared for our kids as they graduate. I don't feel like there are places for them. I don't know what I'm going to do in a year. A year from now, when I'm sitting here in the summer thinking, 'What am I going to do?' I don't know the answer.

Data Sources

Self-Efficacy Scales

Prior to participating in the focus groups, as part of the letter of introduction and consent, the parents were invited to fill out the General New Self-Efficacy Scales (NGSE) and the Transition Specific Self-Efficacy Scales (TSSE). The scales were utilized to spur parent metacognition about their own understanding, knowledge, and abilities in navigating the transition process. These scales also compared levels of self-efficacy between the parents whose children had participated in 18+ programming and parents whose children were in secondary programming. Measured as well was whether there was a difference in parents' general feelings of self-efficacy as compared to their feelings of transition self-efficacy.

The results revealed a total of 12 parents responded to the survey, six for 18+ programming, and six for secondary (grades 7-12) programming (see Table 3). All questions were rated using a 4-point Likert scale (4 = *strongly agree* to 1 = *strongly disagree*), with the exception of question #26, "In general, I am anxious about the transition process," which was reverse coded and the scores were subsequently modified by calculating (5 – response). For both groups, the median responses were at or above the level of "somewhat agree," for all questions

except #26. Nearly all parents indicated they were anxious about the transition process for the students in grade 7-12 and 18+.

Overall, the means and medians for the composite scores were comparable for the two groups of parents, although the parents of students in grades 7-12 showed more variability in their responses, as indicated by the larger standard deviation for both general and transition planning. A test of the difference between the general and transition self-efficacy yielded a Wilcoxon rank sums S statistic of 39.50 with a two-sided p-value of .9762, which falls short of significance.

Table 3*Parent Self-Efficacy Scales of NGSE and TSSE Surveys (N = 12)*

Question #	Question	18+ Programming			7 th – 12 th grade		
		Median	M	SD	Median	M	SD
General Self-Efficacy Scale							
Q16	I will be able to achieve most of the goals that I have set for myself.	3.00	3.33	0.52	3.50	3.17	0.98
Q17	When facing difficult tasks, I am certain that I will accomplish them.	3.00	3.17	0.41	3.50	3.33	0.82
Q18	In general, I think that I can obtain outcomes that are important to me	3.00	3.33	0.52	4.00	3.33	1.03
Q19	I believe I can succeed at most any endeavor to which I set my mind.	3.00	3.33	0.52	3.50	3.33	0.82
Q20	I will be able to successfully overcome many challenges	4.00	3.83	0.41	4.00	3.17	1.33
Q21	I am confident that I can perform effectively on many different tasks.	3.50	3.50	0.55	3.50	2.83	1.47
Q22	Compared to other people, I can do most tasks very well.	3.00	3.17	0.41	4.00	3.50	0.84
Q23	Even when things are tough, I can perform quite well.	3.00	3.17	0.41	3.50	3.33	0.82
	Composite score	27.00	26.83	2.14	30.00	26.17	7.19
Transition Specific Self-Efficacy Scale							
Q24	I believe that I understand the transition process.	3.00	3.17	0.75	3.50	3.33	0.82
Q25	I feel I can give important information to the transition team.	4.00	4.00	0.00	4.00	3.67	0.52
Q26	In general, I am anxious about the transition process.	1.00	1.33	0.52	2.00	1.83	0.75
Q27	I am comfortable giving advice to other group members of the transition team.	3.50	3.50	0.55	3.00	3.17	0.75
Q28	I understand how to suggest/write goals that focus on transition.	3.00	3.33	0.52	3.50	3.33	0.82
Q29	I am confident in the legal aspects of the transition process.	3.00	2.67	0.52	3.00	2.83	1.17
Q30	I am comfortable collaborating with the transition team.	4.00	3.83	0.41	3.00	3.33	0.52
Q31	I am an essential member to the transition planning process.	4.00	3.50	0.84	3.50	3.50	0.55
	Composite score	25.50	25.33	1.75	25.50	25.00	3.58

Document Analysis

Parent active participation in transition planning was needed to develop a relevant program positively affecting post-secondary outcomes for the student and families. To measure how documentation of parent collaboration and participation occurred, I requested IEP documents from all participants. All parents submitted their child's most recent IEP for analysis. The majority, 10 of the 12 parents in the study, indicated that they felt documentation within the IEP contained their contributions to the transition process. But, two of the parents did not report pushing to have specific data included in the IEP. Parent 4 illustrated a heated process to ensure the IEP included all parent input, including transition goals, post-secondary goals, and other concerns, stating,

I asked for the goals to remain. They would not. They would not, and we had to struggle. They did not put it in at first, and I said, "I want the eight-page parent concern in." And sometimes, what I've learned along the way, which I did not know before, but again each year and each month of my son's life, I learn something new. So unless it's in that IEP document, unless it's mentioned at the IEP meeting, it does not count.

Whereas, Parent 3 commented on the lack of specific information in her student's paperwork. "Anyway, I never said [specific information] in an IEP that I can recall. So, I even said it in a meeting with State Workforce, but now that you mention it, I never saw it documented in IEP paperwork." As a whole, parents felt the most crucial area of documentation was the deliberation and minutes of the meeting. Parent 9 summed up this idea, stating,

I have them put all that stuff in the minutes and I have them read it back to me. And then I ask for proof of what we've put in the IEP. "Show me that we're doing this. Show me that this is working or not working."

The majority of parents felt confident their input was documented in the IEPs and that this was a critical action in ensuring services were provided and goals maintained. However, several parents indicated that more important than IEP documentation was the actual IEP

implementation and the input on the goals that the transition plan was being carried out. Parent 8 discussed the importance of the application of the plan:

I'll look at the goals, but I'll also look at day-to-day. Because you can put whatever you want on paper. I want to see actual, what are you planning in class, where are we right now? So, I usually touch base, "How's it going?"

Additionally, only two parents recalled seeing any information from the parent transition inventories within the IEP documentation.

Parents expressed an understanding that if parent input was within the minutes or deliberations, that constituted accurate documentation of parent participation and assured implementation of the transition plan. Parent understanding seemed to be that the deliberations are part of the IEP. The parents expressed more awareness of the deliberations than the parent input delivered through the goals, inventories, or coordinated activities. To determine if the IEPs accurately reflected parent perceptions of their feedback in the transition planning, I analyzed the transition sections, parent input, transition goals, post-secondary goals, and the deliberations of the IEPs for evidence of parent input and collaboration within the IEP (see Table 4). If specific information identified as parent input was present, I indicated a "yes"; if parent input was not mentioned, a "no" was entered within Table 4. I analyzed if the IEP addressed the parent concerns through (a) transition goals, (b) predictions of post-secondary life aligned with the post-secondary goals, (c) parent transition inventories, (d) transition Present Levels of Academic and Functional Performance (PLAAFP), and I deliberations or a supplement. Per the data contained in the IEPs delivered to me, parent input surfaced in 66% of the transition PLAAFP. The parent information reported in the transition PLAAFP was obtained either through inventories or phone calls. The parent's views indicated through reported parent surveys or inventories in 66% of the IEPs; these surveys were often imbedded within the transition PLAAFPs. Interestingly, in almost

50% of the IEP transition plans, goals were aligned with parent input; however, 75% of the post-secondary goals aligned with parent predictions of student post-secondary needs. For example, Parent 3's IEP input showed

The mother identified the following areas that she will require support for: financial management [i.e., money management, budgeting, banking, paying bills], transportation, independent living, recreation/leisure opportunities, job training, social relationships, medical access as areas of skill need.

None of the transition goals targeted any of these concerns; instead, they were primarily behavior-based or a goal to follow general task directions. This observation was not critical of goals implemented or that they were not goals necessary to address deficits, but that the functional concerns of the parent were not incorporated in the transition planning. However, the post-secondary goals for the student did reflect the parent's responses concerning the future living environments of the student: "Upon completing [18+ programming], Student 3 will reside and contribute with daily chores within a group home with supports from agency and family support." The parent's future living input included, "She [mother] states that Student 3 plans to live in a group home."

Parents within the focus groups repeatedly emphasized the importance of the deliberations in the IEP planning process. Therefore, I expected to discover significant parent input within the deliberation sections of the IEPs (see Table 5). Except for Parent 4, the deliberations contained little transition input or parent concerns. Possibly, the team addressed parent concerns throughout the meeting, and the goals or activities were adjusted and not documented as a change within the IEP. However, perusal of the data within Table 4 indicates an inconsistency in applying parent concerns to transition goals or post-secondary goals. The lack of parent input in the deliberations may spotlight a disconnect between parent perceptions of documentation and the finalized IEPs provided for this study.

Table 4*Transition Planning Parent Input: IEP Documentation*

Parents	Trans. PLAAFP reflected parent input	Parent Trans Survey	Trans. Goals aligned w/parent input	Post-secondary goals aligned w/parent input	Deliberations reflected parent input	Supplement of parent input
Parent 1	No	Yes	No	Yes	No	No
Parent 2	Yes	Yes	Yes	Yes	No	No
Parent 3	Yes	Yes	No	Yes	No	No
Parent 4	Yes	No	Yes	Yes	Yes	Yes
Parent 5	Yes	No	No	No	Yes	No
Parent 6	Yes	Yes	No	No	No	No
Parent 7	No	No	No	No	No	No
Parent 8	Yes	Yes	Yes	Yes	Yes	No
Parent 9	Yes	Yes	Yes	Yes	Yes	No
Parent 10	Yes	Yes	Yes	No	Yes	No
Parent 11	No	No	No	No	No	No
Parent 12	No	Yes	No	Yes	Yes	No

Table 5*Transition Planning Parent Input: IEP Deliberations*

Parent	Deliberation Input
Parent 1	Parent indicates no concerns.
Parent 2	Parent indicates that she is in the process of obtaining guardianship for the adult student. They have Power of Attorney and will send a copy to the Case Manager for the state file. Parent will address concerns throughout the meeting. (No additional input).
Parent 3	Parent and student concerns were solicited, they did not indicate any specific concerns at that time.
Parent 4	Deliberations were all parent concerns as this was an IEP meeting that ended in disagreement.
Parent 5	Mom and Dad have a day-hab facility in City (Special Abilities of State) that they are excited about. Their concern is transitioning their family to that part of the (State). They have not been able to find a comparable day-hab facility in (town).
Parent 6	Parent shared that she will address any concerns throughout the meeting. (No additional input).
Parent 7	Parent input was provided in order to update the transition plan. The Parent signed and indicated acceptance of the proposed IEP.
Parent 8	Parent has concerns regarding the limited number of functional goals. She would like the current functional goals to go through May 2020 and then would like to discuss functional goals for the 18+ programs at the Revision IEP in May.
Parent 9	Parent indicated they are looking into guardianship. They are also on the (Local day-hab) list. Parents asked for the HCS Home and Community-Based Services. The parent signed and indicated acceptance of the proposed IEP.
Parent 10	Parent did not have questions to start the meeting. She is much more interested in functional activities in 10's day over academic activities.
Parent 11	Parent indicated agreement with proposed accommodations and did not have any questions. Parent had no concerns.
Parent 12	Mom reports that guardianship will be official tomorrow (2/19/2020). Mom reports that 12 hates going out in the community.

Coordinated Set of Activities. Both IDEA (1990) and WIOA (2014) align in the mandate for a coordinated set of activities to facilitate collaboration between agencies—school

and vocational rehabilitation—to ensure positive post-secondary outcomes for students with disabilities. There was an unintended finding in the analysis of the transition supplements for the coordinated set of activities within the IEP document, specifically the identifying the entity responsible for providing the services for the activity. The results of the examination of the coordinated activity revealed a possible systemic misunderstanding of the intent of coordinated activities. In each IEP, the entity responsible for the activity was not consistently appropriate. The student should not be responsible for providing services, nor should it be the sole responsibility of the family or the parent. In the spirit of appropriate transition planning, I have included the break-down of entities responsible according to the specific IEPs as a point of interest (see Table 6). To develop a meaningful and useful transition plan, the transition team must be conscious of and understand the mandate of coordinated activities between the school, family, and the outside agency. It was interesting to note that none of the IEPs indicated the outside agency as a component of the coordinated activities. The absence of the outside agency as a collaborative partner supports the parent observations that the agencies rarely attended the transition planning meetings.

Table 6*Entity Responsible for Coordinated Activity*

Parent	Student	Parent	Teacher	Parent/ Teacher	Parent/ Student	Teacher/ Student	Teacher/ Parent/ Student	Outside Agency Services
Parent 1	-	3 activities	-	-	2 activities	3 activities	-	-
Parent 2	-	5 activities	-	-	3 activities	-	-	-
Parent 3	2 activities	3 activities	-	-	-	7 activities	-	-
Parent 4	-	1 activity	-	-	-	-	-	-
Parent 5	2 activities	2 activities	-	2 activities	-	-	3 activities	-
Parent 6	-	14 activities	-	-	6 activities	-	1 activity	-
Parent 7	-	-	-	-	4 activities	-	7 activities	-
Parent 8	2 activities	2 activities	-	-	9 activities	-	-	-
Parent 9	-	-	-	-	29 activities	-	-	-
Parent 10	-	11 activities	-	-	2 activities	-	11 activities	-
Parent 11	-	-	-	-	4 activities	-	7 activities	-
Parent 12	-	-	-	-	2 activities	1 activity	1 activity	1 activity

Summary

The voices and perceptions of the parent stakeholders were solicited to answer three research questions pertaining to the transition planning process:

- Q1 How do parents perceive their roles within the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?

- Q3 How do perceived feelings of self-efficacy or knowledge in the transition process of students with significant support needs contribute to the amount of collaboration?

Methods utilized to respond to these questions were focus groups, semi-structured questions, coding of the sessions, peer coders for agreement, analysis of the IEP documentation, and self-efficacy scales. Additional review of the peer observer and primary investigator's debrief as well as member checks lent trustworthiness to the process. The three overarching categories acknowledged were (1) Collaboration, (2) Self-Efficacy, and (3) Parent Role. Within these categories, specific themes emerged: (a) Trust, (b) Transition Programming, (c) Advocacy, (d) IEP Roles, and I Time and Toll. Subthemes supported each primary theme.

The parent stakeholders' responses revealed several key aspects in the transition planning process and the parent's understanding of their roles and participation. Within Theme 1: Trust, it came to light that trust in the teacher, transition team, and district was the driving force in supporting positive collaboration. Revealed also was that the teacher played a key role in establishing trust, but the teacher was not the sole contributor to the maintenance of trust; the district and the IEP team are also players. Theme 2: Transition Programming was another key component in the data analysis. Parents felt that, often, the programming was one-size-fits-all, but they argued that for students with SSN, individualization should be a non-negotiable aspect of the transition program. Theme 3: Advocacy emerged and revealed that being an advocate for their child and others was perceived as the primary role of the parent. Theme 4: IEP Roles highlighted the uncertainty in understanding other team members' roles in the transition planning process. Theme 4 also underlined how parents thought other team members might perceive the parent as a co-member. For the last theme, Theme 5: Time and Toll, parents reported the

difficulties they faced through their efforts to understand the transition processes, which became isolating and were a burden, taking a toll both physically and emotionally.

I analyzed IEP's for documented instances of parent input, but levels of recorded participation did not seem to support parent perceptions of input at the IEP meetings. Another irregularity found in reviewing the IEPs were the coordinated set of activities and the seeming confusion between the expectations of the law and the results found in the IEPs. The analysis of IEPs indicated an inconsistent representation of the parents' voices.

In the following section, Chapter V will discuss in greater depth the answers to the research questions, implications, and suggestions for future transition teams, implications for future research, and limitations within this study.

CHAPTER V

DISCUSSION

Despite over 30 years of laws meant to guide and support collaborative and coordinated transition programming, there remain gaps in the process. WIOA (2014) and IDEA (2004) specifically indicated coordinated activities should be calculated to benefit the child with disabilities in post-secondary environments beginning in the secondary years. The reauthorization of the Rehabilitation Act of 1973 into the WIOA (2014) intentionally included updated language that defined and indicated students with the most significant disabilities might need highly individualized post-secondary planning in the areas of volunteering and community involvement (WIOA, 2014). The reflections of the parents of this phenomenological study revealed important insights into the transition planning. Prior research supports the apparent disconnect in all IEP team members easily accessing or understanding their role within the IEP in secondary planning (Oertle & Seader, 2015; Shogren & Plotner, 2012).

Through the focus group conversations, parents confirmed the categories of Collaboration, Self-efficacy, and Parent Roles as areas of greatest importance. Interestingly some of the most significant elements within these categories emerged as trust, advocacy, and the time and toll the parent spent understanding the transition process. Additional themes of transition programming and the understanding of IEP team member roles contributed to the parent's perceptions of the transition process in its entirety. Specifically, individualization was a concern with all parents across all aspects of the transition planning programming. The study of

Seo et al. (2017) reflected the same need for appropriate individualization for the complex needs and, thus, the supports of the students with SSN.

Restatement of Purpose

The purpose of this study was to analyze parent perceptions and responses to the transition planning process for their child with SSN through their lived experiences. If teams are to construct relevant transition plans that are sustainable and appropriate for post-secondary environments, the parent's expectations, concerns, challenges, and successes of the process must be understood. The parent/guardian will be responsible for the individual with SSN after the public school's entitled environment has ended (Gibbons et al., 2015). There is little research providing insight into the parents' self-efficacy in the transition process or their role as an IEP team member. This study's examination of parent perspectives aimed to provide additional insights into the transition process and highlight balanced transition planning opportunities.

The following research questions were posed to address the concerns of adequate parent participation and to discern parents' views on their adeptness in the process.

- Q1 How do parents perceive their roles within the transition team?
- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?
- Q3 How do perceived feelings of self-efficacy or knowledge in the transition process of students with significant support needs contribute to the amount of collaboration?

From the determined categories of 1) Collaboration, 2) Self-Efficacy, and 3) Parent Roles, the themes of a)Trust, b)Transition Programming, c)Advocacy, d) IEP Roles, and e)Time and Toll surfaced and analyzed. The artifacts of IEP documentation and self-efficacy scales contributed to complete the picture and articulate the parent's common experiences. I used the categories and subsequent themes to address the research questions. While analyzing the responses and

organizing the data, some questions required more than one theme to answer the question fully. I also utilized the appropriate artifacts to lend additional substance and support to the answers.

Research Question One

Q1 How do parents perceive their roles within the transition team?

Advocacy

The role of the parent is complicated and cannot be defined through one distinct category or theme. Two categories of Parent Role and Collaboration were used to answer the first research question. Within the category of Parent Roles, the Theme of Advocacy represented the perceptions of all parents' primary function of their role on the IEP team. Within the subtheme *A: Advocacy for their child*, the parents spoke passionately regarding their role as an advocate for their students. Parents of students with SSN seemed to feel that they were warriors for their child, and the IEP transition meetings could feel like an "us against them" interaction. Significant research reflects that while parents are invited into IEP meetings, the invitation alone does not translate to satisfaction; rather, parents voice dissatisfaction (MacLeod et al., 2017; Turnbull & Turnbull, 2015; Zeitlin & Curcic, 2014). The research supports the feelings of not being a part of the process of being an outsider (MacLeod et al., 2017).

As the parents discussed their advocacy efforts, it seemed that parents felt they were often the only ones working on behalf of their child. Rodriguez et al. (2014) recognized that parents often got involved in their child's education when schools resisted their involvement. The parents of this study also indicated that if they were suspect of the appropriate services or felt like their child needed additional support, they became active participants. Interestingly, while parents communicated the expectation of active advocacy within the IEP meetings, they often expected a disagreement with the team. The observance that advocacy and planning

occurred within the IEP meeting supports Plotner et al. (2018) findings that much of parent input and contributions to the transition process occurred during the meeting. If the transition team waited to plan or illicit parent input within the transition meeting, it was not surprising all parents reported the expectation of a disagreement within the IEP meeting and the need to advocate for their child. The concern for their child and the determination that the child received all of the services and supports that the parent felt necessary motivated the parent to push the team, which in the parent's eyes translated as advocacy. The perception of a deficit in the transition plan encouraged parents to become advocates and seemed to reinforce the anticipation of disagreements or perpetuated the "us against" them mentality. DeFur (2012) proposed the school should intentionally nurture the parent-school relationship through a developed shared vision with the parent for the educational process and student outcomes. Perhaps encouraging active parent involvement from the beginning of the IEP planning could dispel any disconnect within the IEP team. Beginning the transition planning process earlier and with a consistent team might create trust and might increase parent understanding of the transition process, allowing them to participate as an active team member more fully.

Illustrated by Subtheme B: *Advocate for others*, the power of the parent's passion was not limited to their child; 11 of the 12 participants agreed with the need to advocate for all children. Per Zeitlin and Curcic (2014), parents often felt not taken seriously, which could explain the study's parents' perception of not all parents advocating for their children. Some parents' lack of involvement could stem from the systemic barriers to involvement and relegated to an inactive role (Cavendish and Connor, 2017; Hirano, Shanley et al., 2018) or being satisfied with the process and not expecting more from the IEP meetings (Childre & Chambers, 2005). However, this study's participants recognized the lack of other parents' involvement as a

detriment, which could have prompted them to feel it their responsibility to advocate for all students. It became clear through the discussions and assertions that the parent viewed their “fight” was advocacy for all students with SSN. As Parent 10 related, “I do still fight for what I want ...and my fight helps all [students with SSN]” Currently, there is minimal research that outlines the parent perceptions of advocacy for their child is viewed as advocacy for others. This study’s finding of parents’ intentional advocacy for all students adds to the research base of parents’ actions as holistic and broadly aimed at helping the whole population.

The parent role of advocacy implicated the need to advocate in all transition planning areas, including individualization of appropriate goals, secondary environments, and job training. This perception illustrated how the overlap into the Category of Collaboration, the Theme of Transition Programming leading into the Subtheme A *individualization*, affected the parent role of advocacy. The use of multiple themes and subthemes to respond to the RQ 1 of the parent perception of their role illustrated the complexity of advocacy and the need for student-specific individualization. The need to individualize and ascertain that the student with SSN is receiving supports to accomplish the goals and activities is of primary importance. The student with SSN is dependent on assistance in all areas of life.

The parent roles are also represented within the Theme of Transition Programming, subtheme B: *Expectations*. Hirano, Shanley et al. (2018) reported low expectations by the school districts when creating goals. To the contrary, the parents in this study indicated the schools held high expectations. No other research has indicated that the school expectations for transition surpassed that of the parents. While it is encouraging that the schools held high expectations for the student, individualized goals cannot be ignored. Still, parents felt compelled to advocate for more relevant, sustainable goals for their students with SSN. The need for appropriately

calculated individualized post-secondary goals is reflected in the law through IDEA's indicator 13, a measure of accountability to ensure the parameters of transition into post-secondary environments (IDEA, 1990). Unfortunately, there is no longitudinal research following the student with SSN into post-secondary life to gauge if the goals have been met or were sustainable. However, Ruble et al. (2019) recently conducted a preliminary study of post-secondary success focused on students with autism syndrome disorder (ASD), including individuals with more significant challenges, and determined without ongoing support for the student and parent, the success of the post-secondary expectations diminished significantly. This recent research corroborates the experiences of the parents in this current study. Therefore, the team needs to consider the future implementation parameters needed to sustain the goal and plan with these constructs in mind.

The stakeholders who participated in this study identified their primary role as an advocate. Parents felt that they filled a critical need for their child and advocated for all families and children with SSN. It is heartening that the parents viewed their roles seriously but discouraging that they did not consistently feel a part of the team. Perhaps the tradition of the school taking the burden of transition and IEP planning should be updated to distribute responsibility more evenly, incorporating parent stakeholders as more active participants. An even distribution could alleviate the parent feelings of "us against them" and, in the process, develop shared visions of transition (deFur, 2012).

Research Question Two

- Q2 How is parent collaboration/participation in the transition process recorded or documented within the IEP transition paperwork?

Individualized Education Plan Documentation

I looked at the Research Question 2 regarding IEP documentation through the critical lens of the themes and documentation to understand more than just whether parent input had been recorded. It was important to understand how the study themes might affect the end product of the IEP plan. I investigated how the Main Theme 1 Trust and Main Theme 2 Transition Programming might interact with the transition programming's final hard copy representation. Lapses in the accuracy or comprehension of the documentation might ultimately affect the fabric of collaboration, the strength of the student outcomes, and the process's reliability. To provide accurate insight into IEP documentation, I delved into the Category of Collaboration, both Main Themes: 1 Trust and 2 Transition Programming and the areas of the IEP itself. Within the focus groups, I also specifically asked parents how their concerns and input were recorded within the transition programming documents. It was important to determine the parent perceptions of IEP documentation versus the reality of IEP documentation of their participation, through either transition input or concerns regarding transition programming. I then examined actual IEP documentation to determine if the paperwork supported parent perceptions.

Analysis of the focus group responses to the specific query into IEP documentation indicated the majority of parents relied on their input to be documented in the minutes. However, not all parents understood or were aware if the intensive supports and their concerns were included in the IEP documentation. The lack of specific and inconsistent documentation was prevalent throughout the transition IEP discussions. It is possible that the success of a transition plan may rest on vital information provided by the parent. Parent 3 illustrated this point as, upon reflection, she did not remember her primary doubt of the plan's success, written anywhere in the paperwork. Considering that Parent 3 reported the plan was ultimately not successful, the lack of

her documented concern highlights this critical issue. Parent input might have been used to facilitate an adjustment to the plan. Otherwise, parents strongly expressed they made certain that their concerns were present in the meeting's deliberations or minutes, thus in the IEP plan and legally enforceable. The parent's emphasis on the planning document's deliberations and their assertions of rewriting goals within the IEP meeting is mirrored by Shogren and Plotner's (2012) research that most of the transition planning occurred in real-time during the meeting. This study revealed that most parent participants collaborated within the IEP transition meeting and confirmed it was in the meetings that goals were rewritten, and supports were added per parent request. But unfortunately, an analysis of the minutes of all of the submitted plans revealed little in a detailed representation of the parent's information (see Table 5). It is troubling that this collaborative planning was not documented as evidence of parent participation.

I continued my analysis of the sections specifically related to transitioning to understand the extent the parent was represented in the transition planning. The results were less than reassuring. The parent voice in transition planning was inconsistently represented across participants' transition IEPs. In a couple of IEPs, the parent's voice was represented in all sections (i.e., transition survey, transition PLAAFPs, transition goals, post-secondary goals, and deliberations). However, for the significant majority, the parent voice was recorded inconsistently and minimally. In two IEPs, the parent voice was completely silent. However, in seven of the IEPs, the Transition surveys were reported within the PLAAFPs, complying with two of the indicators I reviewed.

Interestingly the parent Transition Survey was represented as a standalone and not mentioned in the Transition PLAAFP for two parents. This lack of consistent and aligned input especially concerns on two levels a) most of the parents felt they had made efforts to have their

concerns recorded, and b) in the planning of students with SSN, the parent is the voice of the student. Examination of the documents revealed that the primary stakeholder was not adequately represented on both of these levels.

Additionally, as previously mentioned, the parent or guardian will ultimately be the primary caregiver of the student with SSN. The relevancy of transition goals reflecting parent concerns aligned to meet post-secondary goals may carry additional weight. Therefore, I analyzed whether the transition-related goals aligned and reflected parent input. Reassuringly, 42% of the transition goals aligned with parent input, and 58% of the post-secondary goals reflected parent prediction of life after secondary grades. While Kurth et al. (2019) were not specifically reviewing transition goals, rather goals in general that reflected parent input, the study results were less encouraging at 30% than the current focus group's results. Ultimately, in this study, the parent documentation did not occur to the extent, or detail parents indicated during the focus groups. Considering that no parents mentioned the Transition PLAAFPs during the focus group conversations and the only discussion of the inventories was inappropriate surveys, there appeared to exist a disconnect and lack of understanding by the parents to communicate and ensure that their input was documented in sections other than the deliberations.

To aptly capture and link the themes and perhaps understand how the lack of consistent documentation factors into the parent's membership on the IEP transition team, I analyzed the Category of Collaboration – the Main Theme 1 Trust and Main Theme 2 Transition Programming. Main Theme 1 Trust indicated that when parents trust the teacher and the team, the comfort with the process was smooth, and the collaboration was productive. While discussing trust and collaboration elements, parents observed they would create or rewrite the parts of the IEP, including goals and supports within the meetings. This process was productive

when trust existed between teachers and the team. Therefore, the parent input occurred authentically through the IEP discussion, but it was not documented in the minutes that changes were made. However, without recording this type of collaboration within the IEP document, it is difficult to determine if the parent input was considered in other areas of the IEP.

Analysis of Theme 2 Transition Programming concerning IEP documentation revealed that though parents' perceptions indicated the inclusion of unrealistic post-secondary goals, the actual Post-Secondary goals in 58% of IEPs aligned with parent documented input. While transition surveys and 18+ job training were determined to be one-size-fits-all by most parents, about half of the time, the transition goals reflected parent inventories or voice reported in the PLAAFPs. It could be that the academic goals rather than the transition specific goals are the focus of parent angst. Parent's concern about the academic goals was relevant as Peterson et al. (2013) reiterated that all goals, not just functional goals, should be viewed as transition goals. All goals, including academic standard-based and functional goals, should be geared to help achieve post-secondary goals. It is necessary to assert that 52% of the transition goals did not align with parent concerns, and 42% of Post-secondary goals did not address parent post-secondary predictions. Triangulating all goals may alleviate the parent concern of relevant academic goals during transition focused plans.

Ultimately, parent input was inconsistently and minimally reported through the finalized IEP transition documentation. When parent preferences or views were recorded, they surfaced in transition PLAAFPs, Transition Surveys, and deliberations.

Research Question Three

- Q3 How do perceived feelings of self-efficacy or knowledge in the transition process of students with significant support needs contribute to the amount of collaboration?

Self-Efficacy

To answer RQ 3, parent questionnaire responses of their self-efficacy were analyzed, and verbal responses within the focus groups were evaluated to determine parent self-efficacy levels. Also analyzed was how parents increased their knowledge and understanding of the process and, in turn, did that knowledge/self-efficacy increase collaboration. Additionally, the elements from the Theme 1 Trust were examined to determine the effects on collaboration. Parents were directly asked if they felt increased knowledge would increase collaboration. Self-efficacy scales stimulated contemplation and offered the parent a clearer understanding of the direction of the study.

Self-efficacy is a complicated precept to dissect and fully understand; Bandura (1977) labeled it as a person's understanding and ability to get things done or accomplish a task. Explaining the term self-efficacy to educators has proven difficult in my experience, and the research of Guskey and Passaro (1994) supports the multidimensional aspect of efficacy. Multiple studies in the last 30 years, measuring self-efficacy, have used the concepts of ability to succeed or complete a task when presenting the concept to teachers to measure self-efficacy (Guskey & Passaro, 1994; Mahler et al., 2018). Therefore, it does not surprise that the parents in this study struggled with the specific term. During the focus groups, parents rarely used the word "self-efficacy" even when used by the researcher. Cavendish & Connor (2017) reported that parents were not comfortable with the IEP process due to a lack of knowledge. Therefore, these same feelings may apply to the transition process, which is part of the IEP planning. Within the self-efficacy category, I evaluated the parent-reported feelings of understanding the transition process through the prevalent theme: Theme 5 Time and Toll and Subthemes: A Personal and B

Resources. I also used self-efficacy scales to prime the parent's reflection and metacognition on their ability to understand and accomplish the transition process tasks.

Self-Efficacy Scales

All parents completed the scales before attending the focus groups. Administering the scales before the discussion was intentionally mediated to help instigate parents' reflections and analysis of their abilities within the transition planning process. I did this to introduce the concept and prepare parents for the topics of the interviews. I applied the Wilcoxon rank-sum test, which is designed to work well with small sample sizes. I examined two separate constructs through medium scores: a) difference in self-efficacy levels between the two scales, NGSE and the TSSE and, b) difference of the efficacy levels between the two groups of parents – 18+ and secondary grades. Neither results indicated significance. The overall difference demonstrated between the scales was $P = .976$ and did not quite rise to the level of significance. However, within the scale examining anxiety levels, all parents indicated greater feelings of anxiety related to the transition process than in the general self-efficacy.

Regarding the results between groups, the analysis again showed no significance. Still, it did reveal greater variability in the parents' responses in secondary grades, which could be an effect of the uncertainty of their knowledge and self-efficacy in the transition process. Parents who have more experience with the transition process or have exited the program showed very similar feelings of overall self-efficacy inclusive of both scales.

When the scales were compared to the responses within the focus groups, the variability of responses was similar to the perception of anxiety across all groups. However, the scales did not reveal the emotional, and physical toll parents felt or the isolation they reported. These intangible and abstract variables can mitigate and explain the differences in verbal responses

versus a survey. Cordel et al. (2016) utilized the NGSE and a modified scale to measure self-efficacy in a mixed methods and pre-test/post-test study measuring the effects of self-efficacy on a ropes course. The results were significant on self-efficacy levels post-test, perhaps due to the pre-post aspect and a much larger sample size. However, the use of qualitative interviews served the same effect as the focus groups for this study to clarify and identify the participants' lived experiences.

Focus Groups

The participants' responses in the focus group revealed parents' true feelings and comfort levels with transition planning and how and from whom they received their information.

Scrutinizing the Main Theme 5 Time and Toll and the Subtheme a) Personal, increased the understanding of the anxiety parents felt in the process. All of the parents reported that their feelings of self-efficacy fluctuated depending on the day and the task. When I delved further to gain insight into the reason for the inconsistency in anxiety and feelings of capacity, the parents revealed the time and toll it took to gather resources and sort through the information was "I think it's basically a full-time job. Transition becomes a full-time job, and I've spent... I'm still working on it," Parent 8 stated. Parents mentioned the uncertainty of the viability of the resources they uncovered. The amount of time, paired with the uncertainty of missing something or getting something wrong, accounted for the inconsistency in self-efficacy feelings.

Parents felt that the schools were not able to help them to the extent that offered true value. Parents indicated a lack of support, primarily because of their perceptions that the teachers were not educated on the post-secondary resources as well as that the transition IEP team typically provided what was mandated by law (e.g., the "packet" and website links to outside agency and guardianship) as opposed to partnering with the parent through the transition process.

The feeling that teachers or the school did not know more about transition seemed to contribute to the feelings of isolation when gathering information on their child's transition options. Research supports the lack of understanding and collaboration about the secondary transition process on the part of the classroom teachers and individual members of the transition team (Oertle et al., 2017; Shogren & Plotner, 2012). Therefore, it is not surprising the parents would report these feelings. Perhaps for the team to better understand their roles in the process, it would be necessary for the team members to understand the evidence-based practices associated with the transition for students with SSN. Thus, with an understanding of the EBP and their roles, the team could provide effective transition services to support students with SSN (Papay & Bambara, 2014). However, a succinct understanding of the EBP may not be consistently occurring (Mazzotti & Plotner, 2016; Oertle et al., 2013). This lack of knowledge could be addressed by following the evidence-based practice of parent supported involvement (Carter et al., 2016) and examining parents' suggestions gleaned from Pleet-Odle et al. (2016) research. This study's findings are similar to Pleet-Odle et al. research: a) open lines of communication, b) communicating about specific training, and c) meaningful collaboration with VRs and the community. Combining and implementing this study's findings with previously established EBP and research could alleviate the extreme feelings of isolation reported by parents in the transition process.

Parents communicated in the subtheme B of Resources, they received the bulk of their information from their personal research via the internet or through networking and support groups or friends. However, even with these outside supports, the parents indicated that, at times, they still doubted their self-efficacy or understanding of the transition process.

The parents also revealed whether the increase in self-efficacy affected collaboration with the transition team or the parent's comfort level in working with the team. The response seemed to depend on the previous positive experiences with the team and perhaps the individual student's needs. The majority of parents expressed they felt if they had more knowledge and had been exposed to transition information earlier, the collaboration in transition planning might have increased. Parents maintained that a central figure in their experience in transition planning was the teacher. The teacher was closely linked to feelings of trust or distrust in transition planning. This observation invites the element of trust into the answer of collaboration levels inclusive of self-efficacy.

An examination of the Collaborative Theory and the Self-Efficacy theory, in combination, offered a window into the crucial element needed to increase the parent's level of collaboration when levels of self-efficacy are increased. This element is trust. Trust is the glue to incorporating these two theories. Kumar and Paddison (2000) reported that trust was not the central factor of the singular Collaborative Theory but would strengthen collaboration. However, the element of trust seemed to become a non-negotiable aspect of incorporating the theories of self-efficacy and collaboration. Parents all reported that collaboration levels increased when the trust was present, both with the teacher and the transition team. Likewise, parents reported when they were more knowledgeable; they were more comfortable interacting and working with the transition team. This comfort led to the revelation that it is not merely increased self-efficacy that drives collaboration, but a powerful mediating factor becomes trust.

Implications for Practice

The findings of this study highlighted specific areas that could positively inform practice for all stakeholders. Parents participants identified areas of challenge as a) consistent

collaboration, b) transition knowledge, both teacher and parent, c) documentation of the parent input in the IEP document, d) individualization of the transition plan, and e) understanding the roles of IEP transition members. Parents provided insight that could assist in transition planning teams in the future implementation of stronger individualized programs.

Transition Frameworks

The parents' concerns bring to light that even within the classification of students with SSN, there are different levels and intensity of supports, again underlining the crucial determination for individualized transition planning and goals to meet all individuals' needs. Utilizing transition frameworks could make this a reality. Transition frameworks should be structured to provide a map or blueprint to the IEP. Teams gearing the plan to address transition beginning at early-childhood education or upon identification could support and provide the student with SSN the complex interventions and planning required for successful post-secondary outcomes. Multiple studies, including Hirano and Rowe (2016), and Kohler (1996), have championed transition frameworks inclusive of all stakeholders and beginning transition early. These theoretical research models leaping conceptual to reality and implemented consistently could address several areas of concern, including the issue of parent and teacher self-efficacy. A systemic framework of philosophy, beginning with the teacher's high pedagogy and self-efficacy, would transfer to the special education team (deFur, 2012). The framework should incorporate teacher and parent training for all team members to participate in transition planning knowledgeably (Hirano & Rowe, 2016). Beginning with the end in mind, the stakeholders must conceptualize desired outcomes before beginning the transition process. The outcomes drive the strategic plans of a purposeful transition team (Osborne & Kugler, 2019). The transition framework accompanied by a flexible strategic plan and intentionally implemented, could

address the concerns of a) consistent collaboration, b) transition knowledge, both teacher and parent, c) documentation of the parent input in the IEP document, d) individualization of the transition plan and e) understanding the roles of IEP transition members

Team Roles

Participants indicated a lack of understanding about the individual roles of the IEP team, specifically the role of the vocational rehabilitation counselor (VR) or outside agencies. This study revealed that the VR's involvement seemed to be lacking in the planning and guiding the needed services, including community involvement and opportunities for continued education or possibly individualized work opportunities for the students with SSN. The VRs play a critical role in guiding students' successful post-secondary strategies with disabilities (Test, Fowler et al., 2009). But there is a breakdown in understanding what is expected of the VR in the transition team (Oertle et al., 2013). Students with SSN, possibly more so than other students, need specialized and detailed planning for post-secondary success (Seo et al., 2017). Providing IEP team preplanning and joint training opportunities could allow both the parents and VRs to develop relationships beyond the IEP transition meeting. When discussing outside agencies, parents emphasized the relationship with a specific VR that engendered progress and beneficial outcomes.

Individual Education Program Documentation

Lastly, school teams historically maintain the IEP paperwork (Test, 2012). The school teams must understand all of the components of the IEP. If schools do not grasp the elements of the IEP, it would be difficult to inform the parents of all the aspects of the plan legally calculated to benefit the student. No parents mentioned the coordinated activities during the focus groups. These activities should have direct import on the successful transition of all students with

disabilities, perhaps even more so for the student with SSN. IDEA (2004) mandates a “results-oriented process” to transition facilitated by the coordinated set of activities. Intentionally including parents in the process could both increase all stakeholder’s capacity and increase the collaboration. But more importantly, the inaccurate documentation of the coordinated set of activities for collaboration indicates that the participant’s schools may not understand the legal expectations. Joint training with parents and school personnel would address both the collaborative aspect, increasing efficacy, and understanding the importance of the IEP. *The Taxonomy for Transition Programming* developed by Kohler (1996) notes process and goals are important and needed aspects within the IEP development framework. Moreover, knowledge and communication are inherent attributes to the IEP and transition process and essential for successful plans and student outcomes. All stakeholder voices must be heard and represented within the document to maintain an accurate record of the programming

Limitations of this Study

This study’s findings were comprehensive and addressed previously unexamined elements, primarily that of parent perceptions of roles and self-efficacy within the transition planning process. Due to the phenomenological study’s lived nature, parents could share experiences and perceptions that may lead to stronger transition planning. However, several limitations to the study must be acknowledged and addressed.

Particularly limiting was the participant sample size. By definition, the population of students with SSN is marginal, and therefore the participant pool is limited. A larger sampling of parents would provide a broader overview of parent perceptions. The diversity of the sample was also singular. All but one parent self-identified as Caucasian, and the other indicated Other. Educational levels were varied, which seemed representative of the population; however, all but

one of the participants lived in a suburb. Participants represented three districts, but the districts were within a 150-mile radius, thus regionally related.

Due to the nature of recruitment, through support group social media sites and word of mouth, it can be assumed that parents were involved in their student's education and actively educated themselves in issues regarding special educations. Upon reviewing the transcripts, this proved to be true. While it is encouraging to see parents advocating for their child, it is limiting in representing a more authentic make-up of parents of students with SSN disabilities, including those who chose not to participate in this study.

The definition of students with SSN used for this study was fairly wide encompassing and was inclusive of students who a) took alternative assessments and b) needed significant in a variety of life-impacting areas (Kleinert et al., 2015; Kurth et al., 2012). While all the participant's children met this criterion, due to the varying levels, ability, and adaptive, of students within this definition, the lived experiences still varied greatly between some parents.

Finally, most of the parents had been part of the transition planning for at least three years, and per the parameters of the study, none were in the primary grades or outside of 18+ for longer than five years. The narrow range of years of transition services mandated by IDEA (1990) limited the study's examination of parents' perceptions in primary grades, preparing for transition, and views of parents whose child lived in post-secondary environments.

Suggestions for Future Research

Insight into the limitations of the study provides a roadmap to future research. It is important to acknowledge all ethnicities and increase the sampling pool's diversity to give minority parents a voice. Additional research could give insight to obstacles for minority families that may differ from this current group of parents. A project continuing to explore the research of

Hirano, Shanley et al. (2018), but widening the scope by examining the specific barriers of minority parents with children with SSN would expand the understanding of more unique challenges and successes of the transition process.

Other options for future research include inviting parents of younger children into the conversation, perhaps middle schools or primary grades. Kohler (1996) underlines that it is never too early to begin the discussion of the transition. The transition frameworks mentioned earlier support early collaborations focused on post-secondary lives.

Additionally, research focused on implementing transition frameworks would suggest a longitudinal study of possible significant implications. Committing to a 15 or more-year study might provide a continued source of data for transition teams. If the studies targeted the student with SSN, the support for evidence-based practices for this population might be increased. While Mazzotti et al. (2016) cemented EBP for most students with exceptionalities, the student with SSN and their families may benefit from EBP research targeting their more unique complexities.

The IEP documentation analysis revealed an inconsistent application of transition plan processes and characteristics. The limited number of IEPs reviewed, and the fact they were provided from the same general region begs expansion of the IEP review scope. It would be interesting to conduct a national study of IEP transition components to reveal what other areas of the country are doing to uphold the spirit of IDEA (2004) and WIOA (2014). The determination of what is working and where the gaps consistently persist could help create more compliant IEPs and support the law's intent to serve students and families post-secondary.

The transition team's work does not theoretically or, in reality, end in the 22nd year. The transition team's actions live past the 22nd year of the student through the successes or inadequacies that post-secondary life brings, determining how well the team did its job. To judge

how well teams create sustainable, well-calculated transition plans, additional research beyond the public-school years conducted at five-year intervals for 15 years could serve this purpose. Ultimately to continue improving, we must have continued research that determines what we do right and where we need to improve all for the sake of our most marginalized.

Conclusion

Parents/guardians as stakeholders are typically the one constant in the students' lives with SSN, from the beginning and beyond post-secondary. They should be considered equal partners in the transition process and the creation of transition plans. The parent is a required member of the transition team, and while other members are required, it is only the parent and the administrator who must sign the IEP document cementing the plan for following IEP year (IDEA, 2004).

This study's purpose was to examine parents' perceptions of their roles and experiences in the transition process and explore their competency in participating in the transition team. Parents communicated that passionate advocacy for their child and other children were their primary goal and primary role in the transition IEP team. It was this goal that did not diminish. Parents held tight to this idea of providing the supports and resources their child needed for post-secondary success. Parents communicated that their goal was met at times through collaboration and, at other times, through challenges and struggles. The parents identified that increasing their self-efficacy, accompanied by trust in the team, increased the collaborative efforts and perceptions of working as a team. But the role of advocacy and efforts to increase self-efficacy did not occur without a cost. The time and toll of anxiety and in physical effort of navigating the uncertain path of transition resulted in the transition process becoming an isolating experience. Ultimately, parents perceived themselves as members of the team, mostly respected but

respected because of their stand for the benefit of the child. As Parent 8 summed up the parent's overall feelings, "It's not just a transition for your kid; it's a transition for you."

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APPENDIX A
INSTITUTIONAL REVIEW BOARD APPROVAL



Institutional Review Board

DATE: April 16, 2020

TO: Elizabeth Osborne

FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [1578554-2] Parent Perspectives on Their Role in the Transition Planning Process of Children with Significant Support Needs

SUBMISSION TYPE: Amendment/Modification

ACTION: APPROVAL/VERIFICATION OF EXEMPT STATUS

DECISION DATE: April 16, 2020

EXPIRATION DATE: April 16, 2024

Thank you for your submission of Amendment/Modification materials for this project. The University of Northern Colorado (UNCO) IRB approves this project and verifies its status as EXEMPT according to federal IRB regulations.

We will retain a copy of this correspondence within our records for a duration of 4 years.

If you have any questions, please contact Nicole Morse at 970-351-1910 or nicole.morse@unco.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Northern Colorado (UNCO) IRB's records.

APPENDIX B

LETTER OF APPEAL TO PARENT GROUPS



Dear (insert name),

I am contacting you as an administrator of _____ Group to request your assistance in disseminating on your site an invitation to participate in a study of parents/guardians whose child is a student with significant support needs and is currently in the transition planning process with an IEP team. The study concentrates on analyzing parent stakeholder perceptions of the collaborative transition planning process, parents' feelings of knowledge, self-efficacy, and levels of satisfaction. The participation of stakeholders will consist of focus groups and is strictly voluntary.

The goal is to compare perceptions of collaboration and feelings of self-efficacy in the transition process to improve future planning practices between stakeholders. Although confidentiality cannot be guaranteed due to the electronic nature of some of the data gathering, every effort will be made to mask participant identity. The results of this study may be published in the professional literature, but no publication will contain specific descriptors. Broad descriptors of geographical location (e.g., medium-sized affluent suburb in a southwestern state) will be used. If permission is granted two groups of 6-8 individuals will be assembled who fit the criteria of families of students with significant support needs. The groups will be divided by guardians whose students are currently in secondary environments (grades 6-12) and those whose students are in the 18+ programming. As we are hoping to have a relevant response rate from stakeholders and considering the low incidence of the population of students, please feel free to pass the survey on to other support groups or parents. I have attached a suggested blurb to post on the " _____ " website.

Thank you for your consideration of this request and informing parents of the opportunity to participate in a study which could inform future transition practice.

Please contact Elaine Osborne osbo2941@bears.unco.edu / cell (469)834-5884 with any questions.

Sincerely,
Elaine Osborne
Doctoral Candidate
School of Special Education
University of Northern Colorado

APPENDIX C
GUIDANCE FOR WEBSITE



Hello Parents!

An opportunity has been shared to participate in a study focused on the parent's perspective of the transition process for your child. You will be asked to share your feelings of your ability to participate in the transition process. How is this vital process going in your opinion, the successes and the challenges! There are a few parameters to the study listed below. If you are interested in participating, please click on the embedded link and you will be directed to a letter of explanation and surveys

- Parents/guardians whose child is a student with significant support needs (i.e., students taking the alternative STAAR-Alt 2 Assessment, needing continued assistance/support in multiple areas of life)
- Currently participating in the transition process (grades 6th-12th) or
- Currently participating in 18+ programming

The study is conducted through short surveys and a focus group with open-ended questions. The study concentrates on analyzing parent stakeholder perceptions of the collaborative transition planning process, parents' feelings of knowledge, self-efficacy, and levels of satisfaction. If you have any questions you can contact the researcher Elaine Osborne @ osbo2941@bears.unco.edu.

Parent Perspective Link

APPENDIX D

LETTER OF INTRODUCTION AND CONSENT



Dear Parent/Guardian

Thank you for interest in participating in the focus group exploring parent perceptions of the collaborative transition process for students with significant support needs (SSN). I believe your perspective will be invaluable to my research and could serve to impact future transition applications.

If you decide to participate in this study, please access the link and complete the brief demographic survey. You will also be asked to complete two short Likert surveys (total of 16

questions) regarding self-efficacy ranging from 1 strongly disagree to 4 strongly agree. Upon completion of the surveys a confirmation email with date and location of the focus group will be sent. Please respond to the email if you can join participate in the specified data and time. Your email will be used to assign you a numerical pseudonym. The surveys should take approximately 20 minutes to complete.

I would like to assure you that your participation in this study is completely voluntary. You can choose to be in the study or not. The focus groups will be audio and video recorded and transcribed; the numerical pseudonym will be aligned with your previous survey responses. All recordings will be destroyed at the end of the study. However, the de-identified transcripts may serve to impact future research in stakeholder perceptions and participations in the transition processes. Each focus groups is anticipated to last 1 hour-1-1/2 hours, however this time may be increased dependent upon your travel time.

Your child's most recent IEP document will be requested in order to analyze recorded instances of participation in the transition planning. Only sections of "Parent Input, Transition Surveys and Deliberations" will be analyzed. IEPs will be de-identified upon receipt, manually if received in hard-copy form and labeled with the assigned numerical pseudonym. Or de-identified utilizing control F and then visually checked and replaced with the numerical pseudonym if received in soft-copy form.

Although confidentiality cannot be guaranteed due to the electronic nature of some of the data gathering, every effort will be made to mask participant identity. All recordings will be transcribed and coded. Transcriptions will be identified only

through the numerical pseudonym. Only the researchers involved in the study will have access. The data analysis file will also be password protected and separate from other files. All audio and video files will be erased upon transcription. If IEPs are provided in hard copy, these de-identified documents will be kept in a locked file cabinet in the primary researcher's home office.

If you choose to participate in the survey and focus group, a light snack will be provided and a 10-dollar Amazon Gift card (\$10) to be received at the end of the meeting. If at some point during the process you feel discomfort you may end your participation with no consequences of any kind. Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Please take your time to read and thoroughly review this document and decide whether you would like to participate in this research study. If you decide to participate, your completion of the surveys indicates your consent. Please keep or print this form for your records.

If you have any concerns about your selection or treatment as a research participant, please contact Nicole Morse, Research Compliance Manager at Attn: Nicole Morse, Office of Research and Sponsored Programs, 3002 Carter Hall, University of Northern Colorado, Greeley, CO 80639, 970-351-1910.

Thank you for considering this research opportunity.

Sincerely,
Elaine Osborne
Doctoral Candidate
School of Special Education
University of Northern Colorado Osbo2941@bears.unco.edu

Sandy Bowen Ph.D., Research Advisor
School of Special Education
Box 141 | Greeley, CO 80639
University of Northern Colorado sandy.bowen@unco.edu -970-351-2102

APPENDIX E

DEMOGRAPHIC QUESTIONNAIRE-FOCUS GROUPS

Descriptive Criteria:

1) Do you have a child with significant support needs?

Yes

No

2) Have you been on a transition IEP team for students with significant support needs in the last five years?

Yes

No

3) To which gender identity do you most identify?

Male

Female

Other

Prefer not to answer

4) Age (years)

20-30

31-40

41-50

51-60

60+

Prefer not to answer

5) Ethnicity

African American

Caucasian

Latino/a

Native American/Asian

More than one

Other

Prefer not to answer

6) Highest Educational Level

High school/associates

Bachelor's

Master's

Master's+

Doctorate

Alternative Certification

Prefer not to answer

7) Geographic area

Urban

Rural

Suburban

Prefer not to answer

8) Years of experience collaborating on transition IEPs with children (ages 3-22) with significant support needs

Less than 1 yr.

1-6 yrs.

7-9 yrs.

9) What grade level is your child currently?

Under 5th grade

6th grade

7th grade

8th grade

9th grade

10th grade

11th grade

12th grade

18 + program

Post-secondary yrs. _____

10) Is your child in a specialized program (e.g. Life Skills, Active Learning etc.)?

11) What is your child's exceptionality?

Additional comments:

Are you willing to participate in a focus group of no more than 6 participants? Practicing social distancing and CDC guidance.

Yes

No

Please provide your email, a numerical pseudonym will be assigned. If you responded YES to the focus group, an invite to the focus group will be sent to your email address.

** What are the best days for you to meet

Weekday Evenings

Weekend Morning
Weekend Afternoon
Weekend Evenings
No meeting

Additional Comments: _____

APPENDIX F
SELF-EFFICACY SCALES

*Self-Efficacy is personal perceptions of the ability of oneself to accomplish tasks or be proficient in an endeavor; how well does a person believe they can do something. “Self-efficacy beliefs determine how people feel, think, motivate themselves and behave” (p.2). Bandura (1994)

Please respond to the following questions assessing your feelings of self-efficacy (abilities) based on a 4-point rating scale using the following key: 1 = Strongly disagree, 2 = Somewhat Disagree, 3 = Somewhat agree, and 4 = Strongly agree

New General Self-Efficacy Scale

Please respond to the following questions assessing your feelings of self-efficacy (abilities) based on a 4-point rating scale using the following key: 1 = Strongly disagree, 2 = Disagree, 3 = Somewhat agree, and 4 = Strongly agree

1. I will be able to achieve most of the goals that I have set for myself.

1 2 3 4

2. When facing difficult tasks, I am certain that I will accomplish them.

1 2 3 4

3. In general, I think that I can obtain outcomes that are important to me.

1 2 3 4

4. I believe I can succeed at most any endeavor to which I set my mind.

1 2 3 4

5. I will be able to successfully overcome many challenges.

1 2 3 4

6. I am confident that I can perform effectively on many different tasks.

1 2 3 4

7. Compared to other people, I can do most tasks very well.

1 2 3 4

8. Even when things are tough, I can perform quite well.

1 2 3 4

Transition Planning Specific Self-Efficacy Scale

1. I believe that I understand the transition process.

1 2 3 4

2. I feel I can give important information to the transition team.

1 2 3 4

3. In general, I am anxious about the transition process.

1 2 3 4

4. I am comfortable giving advice to other group members of the transition team.

1 2 3 4

5. I understand how to write goals that focus on transition.

1 2 3 4

6. I am confident in the legal aspects of the transition process.

1 2 3 4

7. I am comfortable collaborating with the transition team.

1 2 3 4

8. I am an essential member to the transition planning process.

1 2 3 4

APPENDIX G
FOCUS GROUP PREPARED QUESTIONS

Focus Group Prepared Questions

1. Introduce yourselves and your child to the group.
2. How did you find out about transition?
3. How would you describe your role on the IEP team when your child was young?
4. Did/how this role change when the IEP team started planning for life after high school / transition ?
5. How comfortable are you in this current role? Explain more.
6. How would other IEP team members describe your role?
7. What is the most rewarding part of your role?
8. What is the most frustrating part of your role?

9. Throughout the transition process, describe times of collaboration with teammates.
10. During transition meetings, is your input recorded or documented in anyway? How would you rate this documentation on a scale of great to horrible?
11. Does any collaboration occur outside of transition meeting between you and the team regarding transition? Is this input recorded or documented in any way? How would you rate the amount collaboration on a scale of great to horrible?
12. How do you know you have been heard or have collaborated with the team?

13. How do you gather information? Talk about all sources.
14. Talk about your feelings of being knowledgeable/your self-efficacy over the years of the process.
15. What were some of the most successful examples of the transition process? What worked
16. What barriers have you encountered to transition collaboration?
17. Do you think if you knew more about transition, the level of collaboration would change between you and the team? Do you think this would change the outcomes of your son/daughter?

*Since the interviews were semi-structured, the responses of the participants drove the direction and flow of the group. It was my role as the investigator to steer the conversation to answer the research questions. The questions were grouped in an effort to obtain answers to each research question.