August 2020

How Mothers of Children with Significant Disabilities Navigate Special Education Services

Kristin S. Wiseley
University of Wisconsin-Milwaukee

Recommended Citation

Wiseley, Kristin S., "How Mothers of Children with Significant Disabilities Navigate Special Education Services" (2020). *Theses and Dissertations*. 2626.
https://dc.uwm.edu/etd/2626

HOW MOTHERS OF CHILDREN WITH SIGNIFICANT DISABILITIES NAVIGATE SPECIAL EDUCATION SERVICES

by

Kristin S. Wiseley

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

Doctor of Philosophy
in Urban Education

at

The University of Wisconsin-Milwaukee
August 2020

ABSTRACT

HOW MOTHERS OF CHILDREN WITH SIGNIFICANT DISABILITIES NAVIGATE SPECIAL EDUCATION SERVICES

by

Kristin S. Wiseley

The University of Wisconsin-Milwaukee, 2020
Under the Supervision of Professor Laura Owens

This dissertation used a qualitative approach to understand the experiences of mothers of children with significant disabilities from diagnosis through age 21. Specifically, the focus of the research was to identify how mothers negotiated access to opportunities to learn and how they involved themselves in the process of education for their child. The researcher used a retrospective phenomenological approach to the qualitative study. The importance of the study was to make a significant contribution to understanding how mothers see the process and how school systems might facilitate bringing mothers in as meaningful partners so that the partnership can improve the quality of educational outcomes for children with significant disabilities. The findings suggest that mothers were challenged to develop and sustain partnerships with school personnel. The mothers all experienced having at least one person who was determined to be their champion; a person who advocated alongside them to access appropriate educational experiences for their children. The mothers felt it a necessity to be fully involved at all stages of their child's educational experience. Even with all of the mothers having cultural and social capital, they experienced struggle negotiating with school systems. Most of the negotiations started out positive and then transitioned into a struggle with school personnel after starting public education. All of the mothers felt they had to fight for their child to have appropriate access to opportunities to learn at most stages in their child's K-12 education. The findings provide implications for practice including ways that schools can ensure effective parental collaboration by improving communication to strengthen working relationships.

To be gritty is to keep putting one foot in front of the other. To be gritty is to hold fast to an interesting and purposeful goal. To be gritty is to invest, day after week after year, in challenging practice. To be gritty is to fall down seven times, and rise eight.

-Angela Lee Duckworth

This dissertation is dedicated to

the mothers who so generously and bravely shared their stories with me. You are resilient and extraordinary women. Your stories are harrowing yet have incredibly beautiful outcomes. Thank you for letting me into your lives and sharing your moments. This is for you and all the other mothers of children with significant disabilities. You.Are.Amazing. I honor you.

TABLE OF CONTENTS

CHAPTER

LIST OF FIGURES

LIST OF TABLES

ACKNOWLEDGEMENTS

First and foremost, thank you to my major professor and chair, Dr. Laura Owens. This has been a semester full of challenges no one expected! Thank you for taking me on as your doc student for the grand finale, sharing your expertise in this field, listening, encouraging, believing in me and supporting me throughout this process. Your guidance and knowledge have been immeasurable. I feel honored to know you and learn from you.

Thank you to my other committee members for collaborating to make this project as good as it could be through your expertise and direction. Thank you to Dr. Maggie Bartlett, Dr. Amy Otis-Wilborn, and Dr. Raji Swaminathan for lending your expertise to this project. Your belief in me and this study, along with your guidance will never be forgotten.

To Dr. Judy Winn, thanks for listening, encouraging and having puppy playdates.

To my colleagues from the Department of Teaching and Learning at UWM, especially my Exceptional Education colleagues, your support, encouragement, guidance and mentorship has meant so much to me. I will always be grateful for the opportunity to work so closely with all of you. Thank you.

To Dr. Pat Luebke, thank you for your initial and ongoing encouragement for me to pursue this degree. It has been a privilege to work with you, learn from you and have you as a friend. Thank you for providing me with incredible opportunities that led me to where I am today.

To my parents, thank you for the support, always having my back, instilling in me the confidence that I can achieve great (and hard) things and helping me go on when I felt like I couldn’t.

To my grandparents, you have been cheerleaders for me to achieve this doctorate from Day 1. Thank you for all of your questions and interest about the study, checking in, sending congratulations, and believing in my abilities.

To my nieces, Perry and Taylor, thank you for the FaceTime calls, art projects, and love. Sharing stories is one of the best parts of life—so blessed I get to do it with you.

To Brooke, Jill, Jana, Becky, Kari, Kelly, Lauryn, and Carly, thank you for the emotional support I required at a moment's notice, listening ears, words of encouragement, surprise door drops, and understanding when I had to write and couldn't hang. I love you dearly. You are my soul sisters.

To my Goddaughter Calla, I hope you follow your dreams--even ones you think are not achievable. They totally are, girlfriend! Love you and our world traveling adventures. Thanks for being my roomie.

To Miss Wendy, thank you for stepping in to take amazing care of Griff and Mads when my courses and writing my dissertation took priority. So blessed to have you in our lives.

To my fur babies, Griffin and Madison, you were my soft place to land when the work got hard, my late night study buddies, and always there to remind me to make time to play and rest.

And finally, to my husband, thank you for your belief in me, listening ear, shoulder to cry on, encouragement to keep going, and glass of wine (or martini!) when I needed it. I will be forever grateful for the sacrifices you made to ensure that I fulfill this commitment. I heart you!

Chapter 1

Introduction

More students with significant disabilities (i.e., autism, developmental disabilities, intellectual disabilities, multiple disabilities, and deaf-blindness) are entering the educational system, which poses challenges to school systems with regard to delivering effective educational services, including high quality programming that leads to positive post-school outcomes (Anderson, 2009). From an ethical and policy perspective, parents need to be meaningful participants and partners in the process of determining and managing their child's educational experience. As a parent's views change over time, educational systems need to know how their goals and needs evolve related to their child.

There are trends that dictate programming and the availability of resources, which are not always aligned with a child's needs and goals (Ruppar, Allcock, & Gonsier-Gerdin, 2017). Therefore, there is a need to examine the educational process for this unique group of students from a parent's perspective. By using a retrospective process and longitudinal perspective to look through a system's view to identify conflicts, consistencies and dilemmas, the findings will allow educational systems to meet the policy intent and requirement of meaningful parent participation and improve the quality of educational outcomes for students with significant disabilities. As mothers tend to be the primary caregivers (Marcenko & Myers, 1991; National Alliance on Caregiving, 2009; Traustadottir, 1991) and most often the strongest advocate for their child's education (Shuffleton, 2017), this study focused on the experiences of mothers of children with significant disabilities.

Over the years, medical advancements have saved and supported the lives of children with significant disabilities (Woodgate, Edwards & Ripat, 2012), however educational systems have not caught up with these advancements (Anderson, 2009). Consequently school districts are often ill-equipped to educate and support the increased number of students with significant disabilities, as evidenced by parents often using legal action to get appropriate services for their children (Rehm & Rohr, 2002) due to lack of resources and training (Kliebenstein & Broome, 2000).

An unintended outcome of the Individuals with Disabilities Education Act (IDEA, 2004) mandates has led to a focus on compliance and paperwork during the Individualized Education Planning (IEP) process, instead of collaborating with parents and personalizing meetings (Zeitlin & Curcic, 2013). Tucker & Schwartz (2013) pose "parental input is a critical piece in the planning process if we ever hope to achieve educational outcomes that help students and their families obtain personal goals and achieve a better quality of life" (p. 12).

For decades, there has been a trend towards full-inclusion of students with disabilities (Individuals with Disabilities Education Act [IDEA], 2004; No Child Left Behind [NCLB], 2002; Office of Special Education and Rehabilitative Services [OSERS], 2015) without full attention to whether these students were receiving equitable opportunities to learn (OTL), as defined by time, quality and content (Kurz et al., 2014). While school administrators present the process as student and family directed, parents are often not consulted on how and what experiences give their children OTL, along with inclusive educational placements, and are not treated as equal partners in IEP planning and process (Tucker & Schwartz, 2013; Zeitlin & Curcic, 2013). Therefore, conducting an in-depth analysis of mothers' perspectives will help us understand the issues that may lead to equal partnerships.

Significance of the Problem

Research has shown that when mothers are not able to be active partners with school systems and are instead told what is best for their child given an edict to follow, many are not able to develop the skills necessary to productively advocate; may not fully understand their child's disability; and may not learn the know-how to actively and effectively support their child's development, all leading to feelings of ineffectiveness and disengagement from the process (Prizant, 2008). Historically mothers' voices have been absent from the literature. Moreover, the problem involves the disconnect between the school district's compliance of the law and what mothers want for their children's education.

Landmark Court Cases

Landmark court cases have changed the way children with disabilities are educated in schools leading to increased expectations and access. While the law is open to interpretation, the courts have the final say in how school districts are implementing educational programming for children with disabilities. Below are four cases which have impacted programming implementation.

Board of Education v. Rowley, 458 U.S. 176 (1982)

Amy Rowley was a deaf student enrolled in public school. She was provided with a FM wireless hearing aid in a general education classroom and completed that school year successfully. Her parents wanted her to have an interpreter, paid for by the school district, to enhance her educational experience. The district rejected the request on the grounds that Amy was achieving at an average level and therefore did not have to provide services above and beyond. The parents petitioned and took the district to court. The case went to the U.S. Supreme Court, which left the definition up to each state to define FAPE, with guidelines that only some educational benefit was required, not maximum benefit. This case is significant for school districts because it set precedence for services.

Daniel R. R. v. State Board of Education, 874 F.2d 1036 (5th Cir. 1989)

Daniel R. R. was a child with Down Syndrome. Daniel R.R. v. State Board of Education determined that students with disabilities have a right to be included in both general education academic and extracurricular programs. But, the Court stated, IDEA does not contemplate an all-or-nothing educational system. As a result of this case, a two-pronged test was developed for school districts to use when determining appropriate placement (LRE) for a student with significant disabilities: 1) can the child be adequately educated in a general education classroom with supplementary aids and services? 2) If not, has the school included the child in general education to the maximum extent possible for them to benefit from education with typically developing peers? Non-academic gains from social interaction are also considered. After these two determinations have been made, the placement must guarantee that the teacher is not spending so much time supporting a student with a disability that it takes away instructional time and support from the other students in the class; and the teacher is not expected to make modifications so extreme that they reduce the rigor and depth of the curriculum at the expense of the other students. This case was significant for school districts because it helped with placement determination and supported the idea of least restrictive environment and not inclusion as a right for all students.

Oberti v. Board of Education of Clementon, 995 F.2d 1204 (3rd Cir. 1993)

In 1993, Rafael Oberti was a child with Down Syndrome. His parents fought to have him included in general education classes with his peers. The Oberti case established that there is a presumption of inclusion with supplementary aids and services because it is “a fundamental value of the right to public education for children with disabilities is the right to associate with nondisabled peers.” This case established that if placement outside the classroom is necessary, the school district must then include the child in as many school programs with children who do not have disabilities “to the maximum extent appropriate.”

Endrew F. v. Douglas County School District, 580 U.S. ___ 137 S. Ct. 988, 197 L. Ed. 2d 335 (2017)

Endrew was a child with autism who was making minimal progress towards his IEP goals for several years in elementary school. The Supreme Court decided that children who are not educated fully in the general education classroom should have IEPs that are designed with the expertise of school authorities and the input of parents. The IEP is to be designed in a way to meet a child’s unique needs and offering them higher expectations more than the *de minimus* interpretation presented by the school district. While this decision paves the way for higher expectations for students with significant disabilities, it does not define what *appropriate progress* means, nor does it offer specific guidelines for school districts.

Despite these seminal court cases, most educational settings have not progressed enough to be ready to support the educational needs related to students with significant disabilities. Children with significant disabilities have a right to FAPE, to attend school with their peers and be educated with high expectations. The importance of the court cases show the challenges between school district interpretation of compliance with the law and parental expectations for their children. As a district strives to be child-centered, they must be mindful of their relationship with the family. Trust is one of the most important factors for parents with children with significant disabilities. Parents must be able to feel that districts, schools and staff are trustworthy and providing a safe environment for their children. On-going training and support for staff working with the children are essential to best meeting the needs of all involved. These are challenging cases that need to be focused on team collaboration and strong support of all stakeholders.

Need for Research Study

Using a qualitative approach with a phenomenological study offers the mother to have a voice, share her story and perhaps reflect on her experiences through a continuum of the medical model and social model of disability along with the Ecological Systems theory and educational stages/transitions as frameworks. By looking at how mothers navigate educational access, including the strategies they used, I will look at conflicts, consistencies and dilemmas faced by mothers. This study will make a significant contribution to understanding how mothers see the process and how school systems might facilitate bringing mothers in as meaningful partners so that the partnership can improve the quality of educational outcomes for children with significant disabilities.

Theoretical Framework

Three frameworks that are directly related to the issues noted above were identified: 1) medical versus social, 2) Ecological Systems theory, and 3) educational stages/transitions. First, I will present the medical versus social models of disability, leading to a discussion of the Ecological Systems theory, and finally, the educational stages/transitions framework. These frameworks will guide and support the research process and data analysis.

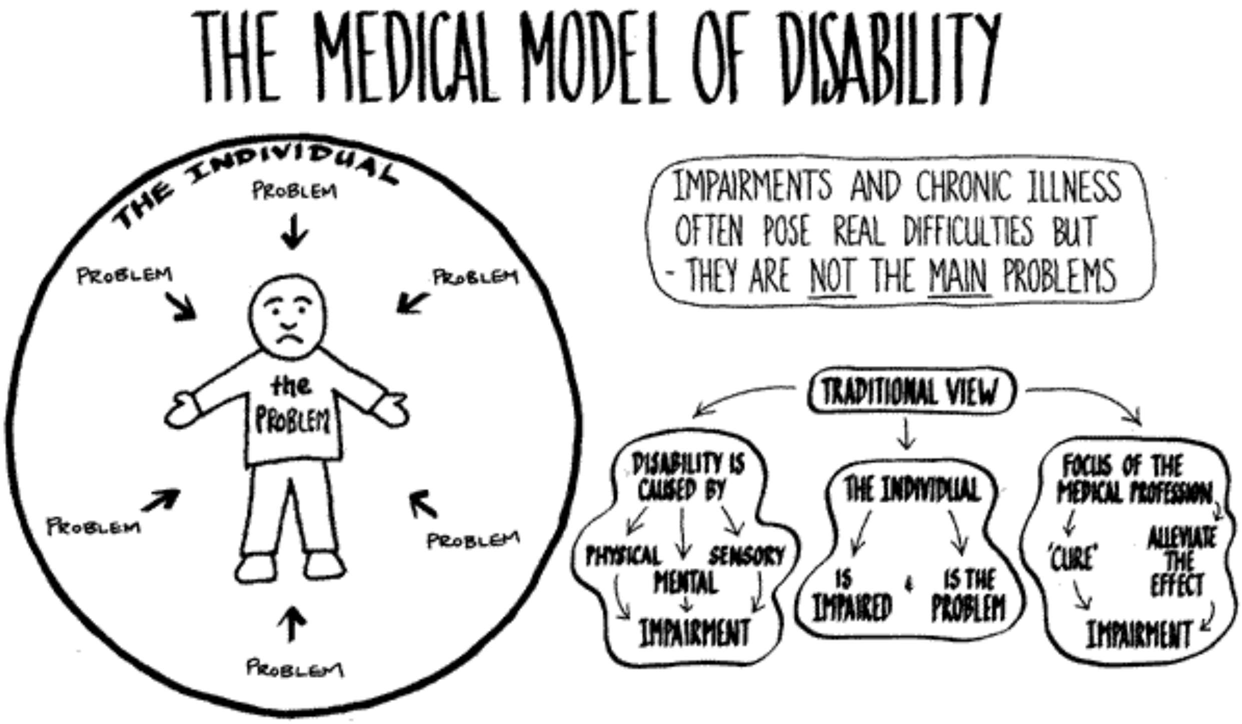
Medical versus Social Framework

Medical Model of Disability

The medical model of disability views disability as something broken and needing to be fixed, as shown in Figure 1. Disability is a “deficit from the norm, a malady to be fixed through physical therapy, technological devices, and personal willpower" (Manago et al., 2017, p. 170). The medical model "...assumes a binary opposition between the categories of normal and disabled and thus has the broadest of social implications" (Landsman, 2005, p. 126). In other words, the medical model is a deficit approach. In the medical field it is a way to "fix" or "cure" but in the education arena it is about normalizing the child in the areas of academics, behavior, functional and social skills. The cynicism of the medical model is that it often forces mothers to engage in wearied and disheartening endeavors to change their children, while not accounting for the mother's positive characteristics and feelings of which they attribute to their children (Landsman, 2005).

FIGURE 1

Medical Model of Disability



Note. Reprinted from the Democracy Disability and Society Group: Medical model of disability, 2003.

According to Landsman (2005), mothers follow the mainstream medical model of disability in an effort to better their child's societal opportunities.

> But over time and in the process of providing meaning to their experience of disability, mothers draw on both the social model's rejection of this individualized, problem-based definition of disability as inherently caused by impairment and their own intimate engagement with impairment as an embodied experience. (p. 138)

However, this duality can create a tension between the mother being caught between the medical model of disability and the social model, finding herself negotiating between the models.

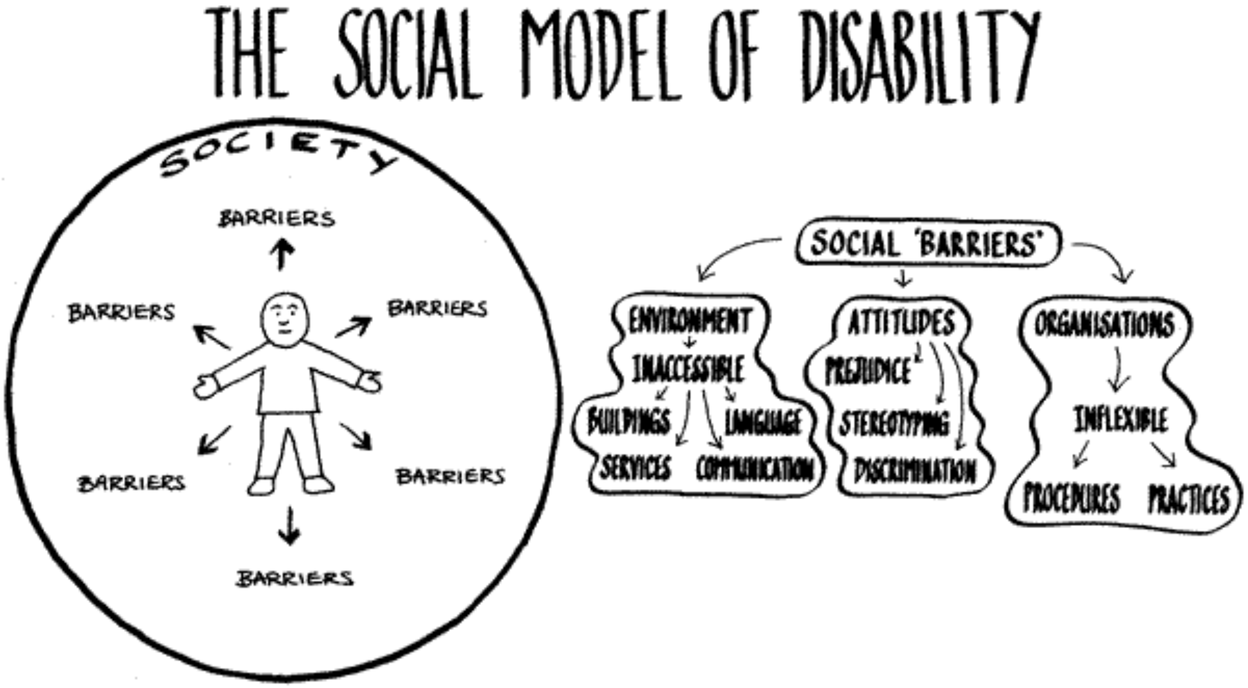
Social Model of Disability

The idea behind the social model is that disability is a social construct and therefore creates barriers for an individual, not the individual's disability being a barrier. This perspective seeks to give people with disabilities choice, independence and control and promotes changes to society instead of changes to the person, as shown in Figure 2. Manago et al. (2017) suggest the social model of disability offers the view of disability as being a form of diversity while being a catalyst for changes to legislation and social views. Pfeiffer (1999) poses disability:

> is not a medical nor a health question. It is a policy or political issue. A disability comes not from the existence of an impairment, but from the reality of building codes, educational practices, stereotypes, prejudicial public officials (judges, administrators, direct care workers), ignorance, and oppression which results in some people facing discrimination while others benefit from those acts of discrimination (p. 106).

FIGURE 2

The Social Model of Disability



Note. Reprinted from the Democracy Disability and Society Group: Social model of disability, 2003.

Pilot Study

In a pilot study, I interviewed mothers of young adults with significant disabilities to learn about their experiences with special education services. These mothers all demonstrated a shift of mindset over the educational experience with their child, as demonstrated in Figure 3. The mothers were immersed in the medical model starting from when their child was born or first received a diagnosis. The discussions with the doctors were often about life saving measures, prognosis, and strongly deficit-based. These feelings align with Landsman's (2005) research which states that

> In interactions with physicians, mothers often encounter this model in the form of the physician labeling the child as permanently outside the range of normal development; mentally retarded, autistic, or motor-impaired with no realistic hope of ever walking,

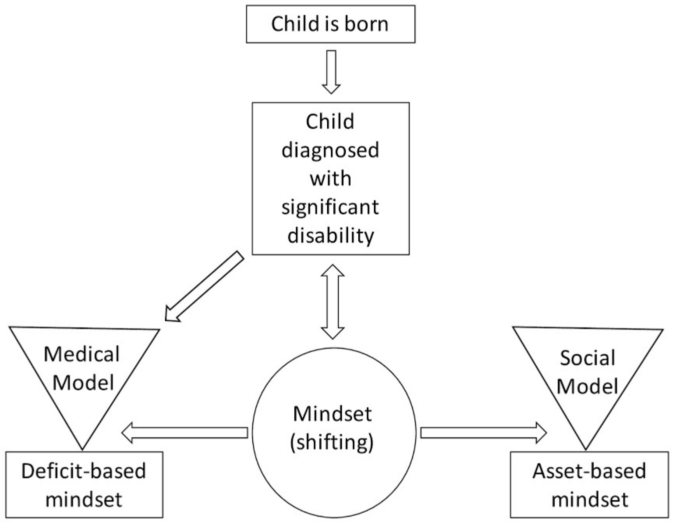
> reaching the academic achievement of their peers, or becoming economically independent. (p. 125)

Over time, all of the mothers had experiences moving from the medical to the social model; their children all started out in segregated early childhood (EC) classes, then were placed in general education classrooms throughout elementary school; finally, placed back in segregated classrooms in middle and high school; as their children got older, the academic gap became wider. As the perceived needs of their child and family changed, mothers' goals and desires for their child evolved. All the mothers wanted the focus of education to be on daily living and life skills rather than sitting in an algebra or world history class where their child would not be able to keep up academically. This mindset shifts from fixing the child, to teaching the child how to become more independent and celebrating the child's abilities, likes and desires for employment or activities post-high school. As the young adult completes high school and the transition program, the social model offers choice and independence through employment and activities in the community. At this time, the social model begins to shape goals and decisions. Landsman (2005) suggests that when "positioned between medicine and disability rights, most mothers simply sought to do the best for their child; in doing so, they combined their awareness of both to retool the social model" (p. 134).

Though mothers interacted with both models, one can argue special education is solely framed within the positivist medical model of disability by upholding the end goal of "normality" in behavioral, intellectual and/or social functioning (Shyman, 2016). In layman's terms: teachers fix what is wrong with the child. However, mothers can be the driving force for the medical model; they suspect something is wrong, receive a diagnosis and begin to focus on how to fix, or normalize, their child. As the medical model is considered to be the sanctioned model, mothers are constrained to engage with it. Although mothers acknowledge a tension between feeling a strong societal pressure to normalize their child while also accepting their child as they are, not many mothers disclose an understanding that their efforts to "fix" their child are despised by disability rights advocates. These multifarious interactions could offer insight into new models of disability (Landsman, 2005).

FIGURE 3

Mothers' Shift of Mindset



Note. Mindset shift chart. From *Parent's Choice of an Educational Setting for their Child with a Significant Disability*, by K. S. Wiseley, 2019.

As depicted in Figure 3, if we think of the process of mindset shift as a pendulum, the mothers began their experience on the far left side operating with the medical mindset: 'my child cannot do this', 'fix my child', etc. When their child started school the pendulum began to move more towards the social model mindset: 'my child is accepted and is who they are'; though special education was working on skills to "fix" the child's deficits. Finally, when the child was in middle and high school, the focus became on learning daily living and vocational skills and strengthening friendships with other children with significant disabilities, shifting towards the middle between these models. It was no longer trying to "fix" the child, yet the child was in a self-contained environment specialized for their disabilities, which could be considered as operating within the medical model.

Ecological Systems Theory

The second theoretical framework is Bronfenbrenner's Ecological Systems theory. This theory helps us conceptualize issues families and children face and provides a framework to support understanding of their experiences, including mothers' negotiations of access and involvement, while helping to explain the shift of mindset (medical model to social model) that occurs as the child ages and advances through the grades, experiencing transitions.

Ecological Systems Theory explains how different environmental systems, such as home, family, school, place of worship, community, and culture, influence how a child and family develop and interact within and between other systems. The five major systems include: micro-, meso-, exo-, macro- and chrono- (see Figure 4).

Microsystem

The microsystem is the immediate environment for a child; where the child lives and with whom they spend the most time, such as their home, school or workplace. The child helps to shape this environment through their interactions and behaviors.

The degree of the microsystem changes with major life events, such as marriages, divorces, births, and deaths (Bronfenbrenner, 1977). Whenever there is a change, that change affects the other parts of the system. In school, the microsystem consists of the teachers, paraprofessionals, other staff members, and peers, which directly influence access to general education curriculum and contexts (Ruppar et al., 2017).

Mesosystem

The mesosystem consists of the relationships between the microsystems. For example, the relationship between the family and the school. In school, specifically in the context of special education, the mesosystem includes the relationship between IEP team members. Consider a child who has experienced rejection and abandonment from their mother. This child may have a more challenging time forming positive relationships with staff members at school.

Exosystem

The exosystem is defined by how outside, or indirect, environments impact an individual, both formally and informally. For example, a father may work long hours at his job, which causes stress for the mother, who may in turn react negatively to their child. Within the context of schools, a teacher's experiences and preparatory education are the exosystem, which can have great impact on a student's access (Ruppar et al., 2017).

Macrosystem

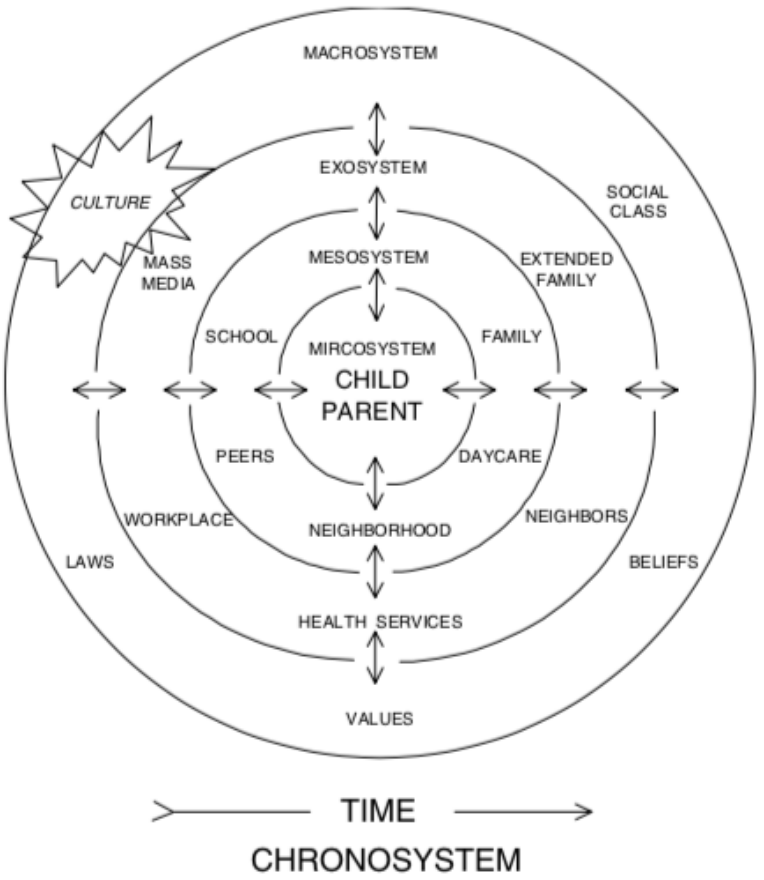
The macrosystem consists of the culture one experiences from where they live, shaping the social structures and interactions in each of the three previous systems, micro-, meso-, and exo- (Ruppar et al., 2017). For example, poverty, ethnicity, and geographical location are determinants. We can think of this in how a culture shapes the experiences and expectations of an individual. The macrosystem also consists of policies and the relationship between those policies, along with a culture and its history. In the context of schools, the placement, instruction and planning for students with significant disabilities is influenced by these factors (Ruppar et al., 2017). Frattura & Capper (2006) pose a student's access to general education contexts are promoted or hindered by the decisions that are made in a school district about the structure of special education services. These decisions are often part of the climate and culture of the district, in other words, the macrosystem (Ruppar et al., 2017).

Chronosystem

The chronosystem is composed of the events and life transitions that an individual experiences throughout a lifetime, including social and historical events. For example, the timing of divorce, a family member's death, or a significant geographical move. As a child with autism matures, their sensory processing ability may improve to where they are able to tolerate crowds, lights, noises and other previously challenging events to their sensory system, thereby increasing their participation in school, the community, and family interactions. Each school transition offers an opportunity to discuss a student's placement and programming. When IEP teams think about transition placement decisions along with instructional configuration and planning, these factors can impact a student's access to general education curriculum and context for the long-term (Ruppar et al., 2017).

FIGURE 4

Bronfenbrenner's Contextual Ecological View of Development



Note. This figure illustrates the relationships of the different ecological systems in human development. (Bornstein & Cheah, 2006) Reprinted from The Place of Culture and Parenting in the Ecological Contextual Perspective on Developmental Science in Parenting Beliefs, Behaviors, and Parent-Child Relations: A Cross-Cultural Perspective (4), by M. H. Bornstein & C. S. Cheah, edited by K. H. Rubin & O. B. Chung, 2006, Taylor & Francis Group.

When Bronfenbrenner's theory is used as a framework, a better understanding of how a family with a child with a disability functions in the system as a whole is developed. We understand that changes or conflicts in one system often impact the other systems. A child's experience in daycare, school, or with friends may impact how they interact with family members in the home, just as experiences at home may impact social experiences, leading to implications for academic, behavioral and social development (Bronfenbrenner, 1977). Through this framework, it is understood that a mother's own childhood, upbringing, and school experience along with her current and past relationships with school personnel and other families at school impact how she interacts with school personnel.

Mothers of children with significant disabilities face transitions and shifts within their ecological systems that greatly impact the functioning of all other systems. The Ecological Systems framework gives support to understanding more than just the aspect of a mother's negotiations for access to special education and involvement in her child's educational programming.

Educational Stages/Transitions Framework

The educational stages and transitions experienced in the lives of mothers of children with significant disabilities are numerous. In the United States, we acknowledge four major systemic transitions: 1) home to school, such as beginning early childhood services, 2) elementary to middle school, 3) middle school to high school, and 4) high school to higher educational opportunities, work or military service (Anderson et al., 2000). In this study, I focused on these four educational stages in addition to the child's birth, diagnosis, and Birth-to-3 intervention. Children, mothers and schools change over time, so using Bronfenbrenner's theory to support these transitions and educational stages gave a strong foundational framework.

Underlying Research Assumptions

As a constructionist/interpretivist researcher, the epistemology is that one's knowledge is subjective; based on one's experienced reality and interactions with others, is driven by the researcher's values and biases, and therefore might conflict with impartiality (Charmaz, 2008; Kawulich, 2012). The focus of this study was on the experiences of mothers of children with significant disabilities. I took into account the multiple realities of mothers through the method of interviewing to hear their stories.

Purpose of the Study

The purpose of this phenomenological study was to answer the research question: How do mothers of children with significant disabilities navigate the education of their children from diagnosis through age 21? I used Bronfenbrenner's Ecological Systems theory and educational stages/transitions as frameworks. There were four key terms throughout this study. The first term *negotiate,* is defined as how mothers are requesting and ensuring their child's special education meets their expectations. The next term *access*, references opportunities to learn and refers to the student experiencing "*intended, enacted*, and *assessed* curricula through the planned curriculum that includes purposefully designed practices in classrooms and schools" (Taub et al., 2017, p. 129). The third term, *involvement*, includes the mothers' participation and decision making in their child's education. *Programming*, the final term, refers to opportunities to learn (OTL), along with inclusive, self-contained, and segregated, meaning education without non-disabled peers. The research question was open-ended seeking to understand how mothers navigate their child's special education, including negotiation for and access to special education along with involvement in their child's educational programming. Developing these narratives gives voice to the mothers of children with significant disabilities that have been historically absent from the literature.

Chapter 2

Review of the Literature

Prior to 1975, children with significant disabilities were often placed in institutions or kept hidden away from society (Landsman, 2005). Only one in five children with disabilities attended school, and those who were in school attended segregated classrooms with limited effective instruction (Currie & Kahn, 2012). Then, in 1975, President Ford signed into law, the Education for All Handicapped Children Act (PL 94-142), now known as the Individuals with Disabilities Education Act (IDEA, 2004), guaranteeing children with disabilities access to a free and appropriate public education (FAPE) in the least restrictive environment (LRE). Subsequent amendments of IDEA have led to an increased emphasis on ensuring students with disabilities have access to the general education curriculum, including general education settings, and accountability for achievement of students with disabilities (IDEA, 2004).

It is important for individuals who do not have a background in special education to understand the concepts and policies that pertain to special education and students with significant disabilities. These concepts are important to understanding the history of special education and current practice in providing services to this population of students.The field of special education has changed dramatically over the past 45 years when the first federal law was put into practice to ensure the education of students with disabilities, including understanding how current policies have evolved and how placement and programming is determined for students with disabilities. As the law mandates parents' participation in their children's special education, it is important to understand the manner in which parents engage with the process along with factors that impact this engagement.

The following areas will be discussed in this chapter: legislation; educational services; opportunities to learn; parental expectations and involvement; and capital. Each section includes subheadings pertaining to the area. Legislation will explore the subheadings of the Individuals with Disabilities Act and interpretations of IDEA. Educational services will explore the two educational settings of inclusion and self-contained, along interpretations of LRE. Parent expectations and involvement will explore parental choice, stress, advocacy, family partnerships, and conflicts. Finally, capital will be presented in regards to how it pertains to parents' interactions with the school system.

Legislation

Individuals with Disabilities Education Act

There are six principles of IDEA: FAPE; LRE; the right to an independent evaluation; procedural safeguards to ensure rights of children and parents are protected; an individualized education through an IEP; and finally, parent participation, which is the pertinent principle for this study. IDEA (2004) states that parents have the right to request an independent educational evaluation, paid for by the school district, thereby implying that parents will advocate to obtain appropriate services for their children with disabilities (Trainor, 2010a). IDEA (2004) directs the equal partnership of schools and parents in the IEP planning and process. In keeping with this mandate, schools present the process to be student and family-centered by inviting students and parents to IEP meetings, as required by law, yet often students and parents are not consulted on their desire for OTL and inclusive educational placements (Tucker & Schwartz, 2013; Zeitlin & Curcic, 2013). Studies have shown that important decisions are often made by staff members excluding parents before the IEP meeting begins (Mehan, Hertweck, & Meihls, 1986; Ruppar & Gaffney, 2011; Trainor, 2010a). Turnbull & Turnbull (2015) assert having a team that "values, honors and esteems the student" (p. 55) and the danger of team members who do not, is just as important to IEP planning and process as are the IEP-specifics of programming, placement and supplementary aids and services. They also proposed changes to evaluation of school personnel to include expectations for treating children and parents with dignity, as it is a principal of the Council for Exceptional Children's Code of Ethics (Council for Exceptional Children, 2015). It should be noted that school personnel could experience tension between representing the school system and also advocating for children; therefore, advocacy transfers mainly to the responsibility of parents (Trainor, 2010a). Lalvani and Hale (2015) argue the design of PL 94-142 and IDEA, which emphasize individualization in advocacy, though were originally designed with civil rights in mind, erodes the greater intent of achieving social change and assuring rights for all people, not just those with capital and high socioeconomic status, leading to reinforcements of inequities.

While IDEA was established to ensure the free and appropriate education of students with disabilities in the least restrictive environments, along with mandating parent participation**,** several challenges have arisen over the years in the interpretation of the law, leading to landmark court cases that have shaped the interpretation of the law. These challenges include educational services, OTL, and parent expectations and involvement for students whose disabilities are considered significant.

Educational Services

IDEA mandates that students eligible for special education services to be educated in the least restrictive environment (LRE) to the maximum extent appropriate with students without disabilities. The segregation of students with disabilities should only happen when the disability is so severe that the use of supplementary aids and services in the regular education environment is not satisfactory (IDEA, 2004). Over the years, the interpretation of LRE has been called into question. According to the most recent report to Congress (41st Annual Report to Congress on the Implementation of IDEA, 2020), 17% of students with intellectual disabilities and 13.3% of students with multiple disabilities were educated inside the general education classroom 80% or more of the school day. Almost half of students with intellectual disabilities (49.2 percent) and 46.1 percent of students with multiple disabilities were educated in the general education classroom less than 40% of the school day, which shows us the prevalence of students with significant disabilities receiving their education in a segregated placement.

Under IDEA, the IEP drives placement decisions, though research indicates schools provide options for placement depending on factors, such as significance of disability, school operations and staffing, and geographical location, not based on the child's unique needs (Brock & Schaefer, 2015). Typical placements include a public school with inclusive and segregated classrooms for special education, such as resource rooms and self-contained classrooms. Inclusive classrooms are settings where students with disabilities are educated alongside non-disabled peers in the general education curriculum, with specialized supports in place to ensure access to the curriculum and environment. Segregated classrooms are settings where students with disabilities are educated only with peers who also have disabilities. These classrooms include a resource room, which is a classroom where students with disabilities receive specially designed instruction from a special education teacher to meet their goals towards accessing the general education curriculum; and a self-contained classroom where students with disabilities receive their education from a special education teacher in a segregated environment. Another placement option is a segregated school for students with disabilities, of which only students with disabilities attend.

Inclusive Classroom

IDEA ensures that students with disabilities have access to the general education curriculum and LRE, not inclusion, though some states and districts interpret LRE to be inclusive classrooms. Downing (2005) posits that the goal of inclusion is for all students to learn and be challenged at their full potential. Inclusion is a philosophy that students with disabilities are educated in the general education classroom with non-disabled peers. According to Morningstar, Kurth and Johnson (2017), research has shown that students with high-incidence disabilities (learning disabilities, other health impairments, and emotional behavior disorders) have increasingly been educated in inclusive settings with non-disabled peers. According to Meyer, Eichinger and Park-Lee (1987), the five best practices for educating students with significant disabilities are: inclusion, home-school collaboration, staff development, data-based instruction, and the criterion of ultimate functioning (preparing students to function in current and future environments). Though these were developed in the late 1980s, these quality indicators maintain relevancy. More current studies reinforce those findings from over thirty years ago and further our understanding by showing the successful components of educating students with significant disabilities in general education settings are 1) a teacher's qualifications, including content and pedagogical expertise (Jimenez et al., 2012); 2) age- and level-appropriate materials (Hunt, McDonnell, & Crockett, 2012); and 3) learning alongside non-disabled peers (Carter et al., 2010).

Benefits of Inclusion

Parents who feel that an inclusive classroom for their child is more appropriate, desire academic and social benefits that align with their child's education in the general education classroom, including participation in extracurricular activities. Parents of children with significant disabilities with higher level skills and less support needs tend to favor more inclusive and integrated environments for their children. These parents believe the inclusive environments offer higher expectations with greater challenge and stimulation, as well as non-disabled children being exposed to children with disabilities (Palmer, Fuller, Arora, & Nelson, 2001). Matzen and colleagues (2010) found students with significant disabilities received more exposure to grade-level academic content when they were educated in general education classrooms, than when they were educated in self-contained classrooms. While some parents may view the general education system as being unwelcoming and unaccommodating, parents that have a view of the system as accommodating and welcoming are more likely to favor inclusion. Lalvani (2013) found parents who favor inclusion tend to view what society says about what is considered "normal" and its views on disability. Therefore, they seek an educational system and lifestyle that is as "normal" as possible. These parents liked the sense of community they felt with their child learning together with non-disabled peers, and hoped for a sense of community in other settings outside of school as well (Downing & Peckham-Hardin, 2007).

Studies have shown students with significant disabilities experience social benefits from being in an inclusive environment. The most important benefit has been found to be students with significant disabilities having increased social interactions with same-aged non-disabled peers (Ballard & Dymond, 2020; Carter & Hughes, 2006). Other studies have found students' social skills and communication improved after having access to inclusive settings, including general education curriculum (Fisher et al., 1998; Matzen et al., 2010).

Participation in extracurricular activities is a student right under IDEA (2004). There are many barriers facing students with significant disabilities when it comes to equal access, including staff not having the skills necessary to support this population along with low-expectations of student participation (Carter et al., 2010). Special education teachers were found to strongly believe the value in students with significant disabilities participating in extracurricular activities with non-disabled peers, though they did not feel they should take the lead role in facilitating participation (Pence & Dymond, 2016). The inclusion of students with significant disabilities in extracurricular activities requires all stakeholders to be active participants in planning for a student's successful participation.

Conflicts with Inclusion

Though the IEP drives placement, parents can be a driving force for or against a specific placement for their child. Parents who do not want full inclusion for their children, typically have children with the most significant special needs (Palmer et al., 1998; Palmer et al., 2001; Lalvani & Hale, 2015). These parents questioned the benefit of the inclusive environment for their children and feared them being unwelcome and unaccommodated. Some parents feared their child would be socially isolated or rejected by their peers. Socialization is often used as a strong reason for inclusion by advocates (Evans et al., 1992; Hall, 1994; Lipsky & Garner, 1997; Strully & Strully, 1996). However, a study conducted by Palmer et al. (2001), few parents cited improved socialization as a benefit.

Matzen and colleagues (2010) studied the general education access of students with significant disabilities in middle school. General educators may feel stressed having the additional responsibility of educating students with significant disabilities to meet state standards, so in an effort to lessen this stress, school administrators reported their intent for educating this population in general education classrooms was for the development of social skills and not academic gains. This view led to students not being fully accepted and being seen as visitors instead of part of the class.

There is a pervasive fear that general education teachers are not prepared or unwilling to teach children with significant disabilities (Leyser & Kirk, 2004; Palmer et al., 2001; Ryndak et al., 2008). Parents who were fearful of their child being socially isolated or rejected by general education peers, along with being uncertain of the qualifications of general education teachers to teach their children, tended to feel that self-contained environments were a safe haven where children with significant disabilities were always welcome and accepted and had teachers who were specifically trained to teach them and meet their needs (Connor & Ferri, 2007; Lalvani, 2013). It is not uncommon for general education teachers to have fears about effectively teaching students with significant disabilities; most are unsure what they will be able to teach these students (Jorgensen & Lambert, 2012). In order to effectively teach students with significant disabilities, these teachers require a specialized skill set that most do not learn in their teacher preparation programs. Most general education teachers have only taken one or two introductory courses on teaching students with disabilities as required by their teacher preparation programs (Young, 2011), leading to teachers not feeling adequately prepared to teach this population. In addition, special education teachers may only have a cross-categorical teaching certification and not intricate knowledge on teaching students with significant disabilities (Agran et al., 2020).

In a study by Palmer, et al. (2001), parents of children with significant disabilities were asked their beliefs on inclusive classrooms. Parents feared that their child would be unwelcome or not accommodated in the general education classroom, while also questioning the benefit of an inclusive environment. However, parents who had a view of the general education classroom as accommodating and welcoming were more likely to favor inclusion. Notably, parents who were against inclusion may have felt that the inclusion movement happened without their input and consent and may have viewed it as an experiment for education or social purposes, with risk of their child's well-being.

Ongoing professional development is required to facilitate and support a common vision and understanding, in addition to constant evaluation.While research has supported inclusion in general education for students with significant disabilities, lack of appropriate OTL, including access and content has been shown in practice (Kleinert et al., 2015). Lack of appropriate OTL may be due to special education teachers not having the ability or resources available to implement the individualized services of all their included students each day (Agran et al., 2020). School systems' resistance to change remains deep-rooted, as evidenced by what is occurring in practice does not align with what is known about providing OTL for students with significant disabilities alongside their non-disabled peers (Ryndak et al., 2013).

"The failure to clarify the possible cost of full inclusion to the learning environment on other students and the teacher ignores some of the most important components of the community of learning" (Dupre, 1997, p. 857). In other words, there are several factors that are often overlooked when a school system transitions to a fully-included model, including the needs of non-disabled students and the teacher. For example, general education teachers are often not prepared for educating students with disabilities in their classrooms. Studies have found team members do not share a common vision and understanding of inclusive education, as evidenced by inconsistencies with inclusive practices leading to a compromise of high-quality education for students with significant disabilities (Barnitt et al., 2007; Downing & Peckham-Hardin, 2007; Matzen et al., 2010; Ryndak, Jackson, & Billingsley, 2000). This lack of vision and understanding is related to limited professional development and training in how and what to teach students with disabilities in the general education classroom.

Self-Contained Setting

Self-contained settings are classrooms where students with disabilities are educated alongside other students with disabilities with limited interaction with non-disabled peers. These settings are sometimes referred to as segregated settings, since they consist of only students with disabilities. Morningstar, Kurth and Johnson (2017) found students with significant disabilities are more likely to be educated in segregated settings, especially in urban and suburban districts.

Most students with developmental disabilities spend the majority of their day in separate classrooms or schools (Brock & Schaefer, 2015). "State and district differences in education placement suggest that factors other than individual student strengths and needs are affecting educational placement" (p. 162). Brock and colleagues found that students with significant disabilities in urban districts spend less time in general education classrooms. A factor for this could be the economically viable option to create self-contained classrooms due to having more students with disabilities in the highly populated area. In contrast, students with disabilities in rural districts spend more time in general education classrooms. This could be due to less funds to create centralized special education programs, so it becomes an economic necessity to place students in general education with support. School districts might include students with disabilities in general education classes to be more economical, though some studies have found inclusion to use more resources than pull-out programs (Dupre, 1997; Brock & Schaefer, 2015). However, per IDEA, placement is to be determined based on where the student's IEP goals can best be met, not the financial cost of a continuum of services.

Benefits of Self-Contained

Lalvani (2013) found mothers who prefer self-contained settings do so because of the feeling of belonging their children would likely feel being with similar peers, as well as their own perceptions of this setting being a safe environment for their children. Mothers perceived the special education teachers in a self-contained classroom to have greater expertise in how to educate their child along with the availability and use of specialized equipment in this type of classroom to be benefits of this environment.

When making decisions about a student's IEP and placement, the importance of person-centered planning is paramount. Person-centered planning in schools looks at the student's goals and needs, including current and future, along with the student's preferences (Browder et al., 2014). Cartledge, Gardner & Ford (2009), stressed the importance of beginning planning with students and their families early to be sure culture, contexts and personal preferences are relevant. Parents desire life skills education which is often not taught in general education classes. The focus of daily living skills shifts as students age. Younger students should be learning self-care skills with adaptations to maximize their independence. Instruction for older students should focus on daily living and community skills (Browder, et al., 2014). All of these skills can be taught effectively using systematic instruction (Keen, Brannigan & Cuskelly, 2007; Mechling, Gast & Seid, 2009). According to Browder and colleagues (2014), "effective strategies to promote these skills include (a) task-analytic instruction, (b) self-management, (c) social narratives, and (d) video and computer-based models" (p. 28).

Transition instruction should be done in the community to increase generalization using systematic instruction. Many studies have shown that positive post-school outcomes are strongly correlated with the quality of transition programs (Carter et al., 2013; Newman et al., 2011; Wehman, 2013; Wehmeyer, 1992). These positive post-school outcomes are also shown to be strongly affected by self-determination (Wehmeyer & Schwartz, 1998; Wehmeyer et al., 2012). Students with significant disabilities often do not have agency to make their own choices.

However, they should be provided with opportunities to do so. The opportunity to make choices is one element of a larger group of skills known as self-determination skills (Browder et al., 2014).

Conflicts with Self-Contained

It is more challenging for a teacher to maintain an atmosphere of high learning expectations when students with significant disabilities are in a self-contained classroom (Downing, 2005). In self-contained classrooms, the other needs of students (i.e., health care, positioning) can easily become the focus, which reduces the time allowed for teaching and learning as teachers and paraprofessionals are attending to students' basic needs instead of focused on academic content; therefore, academics could also be seen as less important (Downing, 2005).

The long-term outcomes of educational placements (i.e., general education or self-contained) have not been determined or studied well-enough to provide informative and reliable evidence or direction of future best-practice. Once formal schooling ends at age 21, young adults with significant disabilities will enter the workforce (ideally), attend day programs, or remain at home. More studies need to be done to determine the post-schooling outcomes based on educational placement. While I believe in inclusion, when done with evidence-based practices, I do not agree with educating all students based on disability labels in either full-inclusion or self-contained. Per IDEA, a student’s placement should be based on where their IEP goals can best be met, not based on disability label, district operations or someone’s opinion. I believe in a continuum of services. “Educational systems inherently resist systemic changes in services leading to substantial lags between what we know about educating students with significant disabilities in general education contexts and what occurs in practice” (Ryndak et al., 2013). The push for inclusion is rooted with good intention; however, my observations of the practice share Ryndak and colleagues' finding. If we claim the IEP is indeed individualized, then it needs to follow its title and individualize for the child, including placement. This most certainly will require intensive and ongoing training for teachers and staff, including administrators, as they follow the law and what is right for children, is to provide access to the least restrictive environment and offer a free and appropriate education.

Interpretations of LRE

Least restrictive environment (LRE) is defined as students with disabilities being educated alongside non-disabled peers in the general education environment to the maximum extent appropriate and that students with disabilities are only educated outside of the general education environment when their disability or needs are so significant that the education in a general education environment cannot be satisfactorily achieved. As such, school districts must consider a continuum of services, where depending on the best environment for a student to meet IEP goals may be an inclusive general education classroom or a self-contained class. This continuum also includes home and residential settings. All of these settings allow a student to receive FAPE while also following LRE based on the student's unique needs and abilities.

In the state of Wisconsin, school districts are eligible to receive reimbursement for special education costs at a rate of about 25% (Wisconsin Department of Public Instruction, 2019). With that seemingly limited amount, an argument can be made around the cost of providing FAPE to students with significant disabilities in general education classrooms, due to the amount of supplementary aids and services the child would likely require to access the general education curriculum. Although financial resources are a limitation for school districts and some might use inclusion to be more economical, studies have found inclusion to use more resources than self-contained programs (Dupre, 1997). Often districts use caution with spending all monies on one student or group instead of all students. The Eleventh Circuit Court determined if the cost to educate a child with a disability in a general education classroom is so high that it would negatively impact upon the education of other students in the school district, then providing education for one child with a disability in a general education classroom is inappropriate (Dupre, 1997). As LRE is open to interpretation in districts, the availability interpretation allows districts to strongly consider resources when determining placements (Carson, 2015). This means that districts consider available funds when making decisions more over the mandates of IDEA. A more recent study found evidence of discretionary placement of students with significant disabilities based on funding sources (Dhuey & Lipscomb, 2011). Though the IEP is mandated to drive placement, funding of students with significant disabilities could be an undisclosed factor in placement decisions.

Landsman (2015) points to conflicts mothers experience with the inclusion discourse and the interacting medical and social models. As mothers have a desire to accept and embrace their child, they are conflicted with the inclusion discourse of students making social and academic gains in this setting, with the belief that they will be judged if their child does not continue to make progress towards normalcy. However, Palmer et al. (1998) provide evidence of parents of children with significant disabilities favor segregated environments for their child's social well-being. This creates conflict with schools' prevailing discourse where a school may favor another prevailing view (e.g., inclusion or segregation). The extant literature tells us there is a gap between research and practice and what is actually available to students (Ruppar et al., 2017). Parents often are the voice for students with significant disabilities, therefore, including parents as meaningful partners is crucial for meeting the student’s needs and desires in order to increase positive student outcomes.

Opportunities to Learn

Opportunities to learn (OTL) is defined by time, quality and content (Kurz et al., 2014). Taub, McCord and Ryndak (2017) pose:

> opportunities for learning must comprise access to the intended, enacted, and assessed curricula through the planned curriculum that includes purposefully designed practices in classrooms and schools that utilize a combination of (a) universal design for learning (UDL) principles, (b) ecologically identified individualized content embedded within the elements of OTL, and (c) supports and materials that enable students to fully and actively participate and make progress in the intended curriculum across the school day (p. 129).

The second challenge to IDEA is how districts are providing OTL to students with disabilities. Educating students with significant disabilities in general education classes requires a skill set and knowledge of how to meet students’ needs, while also ensuring they are meeting IEP goals. Special education teachers need to have the knowledge of how to include students with significant disabilities in general education (Delano, Keefe, & Perner, 2008-2009), including coordinating and training staff, assessments, technology and content knowledge (Leko et al., 2015; Lignugaris-Kraft et al., 2014). Further, teachers need to understand academic interventions in order to teach so students can show progress towards state academic standards (Browder et al., 2014).

Skills for Meaningful Inclusion

It takes a team of professionals to support a student. “In contrast to multidisciplinary teaming in which individuals typically work independently of each other providing fragmented services, students with significant disabilities often have multifaceted needs that require collaborative teaming to develop and implement effective educational supports” (Browder et al., 2014, p. 35). All team members should have shared expectations for the student. There is limited research on collaborative teaming, however.

Paraprofessionals are often used as a support for students with significant disabilities. Browder and colleagues (2014) explain the necessity for “explicit training of paraprofessionals related to disabilities, teaching strategies, content knowledge, and the importance of social interactions can increase the effectiveness of their involvement in the academic and social growth of students with severe disabilities” (p.43).

Skills to Provide Meaningful Accommodations and Academic Interventions

Applied behavior analysis (ABA) has led to the development of systematic instruction. Systematic instruction is shown in research to have a strong evidence base to teach academic skills to students with significant disabilities (Browder et al., 2009; Morse & Schuster, 2004).

How does one use systematic instruction? First, we define the skill to be taught that is observable and measurable. Then we determine if the skill is discrete (single), chained (a series) or task analysis. Task analysis involves breaking tasks into single, or discrete, steps. This can lead to a chained task, which is a series of single behaviors that combine to become a complex behavior (Alberto & Troutman, 2009). This method is often used to teach community and daily living skills (Browder et al, 2014). It can also be used to teach academic skills. After the skill determination, the teacher is able to plan their system of prompts for student response as well as the system to fade the prompts (Wolery et al., 1992). “These systems include simultaneous prompting, time delay, system of least prompts, most-to-least intrusive prompts, and graduated guidance” (Browder et al, 2014, p. 12). Reinforcements should be used for correct responses, always including praise and sometimes tangibles, as needed. Finally, there should be plans for generalization. Once systematic instruction has begun, the student’s responses can be used for data collection and progress monitoring, and thus, teachers can refine their system as necessary.

Three evidence-based strategies for teaching students with significant disabilities are peer-delivered instruction, technology, and self-directed learning (Agran et al., 2006). Peer Tutoring (or peer-delivered instruction) involves training non-disabled students (peers) to instruct students with disabilities in a general education classroom. Using peers for instruction also has shown to promote social interactions and engagement (Browder et al., 2014). Using this one-on-one strategy showed students with significant disabilities received almost constant instruction; whereas when students with significant disabilities were in self-contained classrooms, they were instructed mostly in large-group formats and did not receive as high of a percentage of instruction (Matzen et al., 2010).

Technology has shown to be effective for teaching students with significant disabilities. Video modeling for social skills and daily living skills is consistently reviewed in the literature to be best practice (Bellini & Akullian, 2007). This can be done through computer, iPod or iPad. The use of assistive technology (AT) can improve the student’s ability to function (IDEA, 2004). AT is used for instruction, access to and usability of materials, positioning, daily living skills, as well as communication.

Self-directed learning helps students gain autonomy. Two strategies for teaching self-directed learning are pictorial self-instruction and the Self-Determined Learning Model of

Instruction (SDLMI). Pictorial self-instruction includes having students use picture schedules to complete a task and for social skill development (Browder et al, 2014). SDLMI teaches students to set a goal, take action and adjust the plan as necessary (Wehmeyer et al., 2000).

Universal Design for Learning (UDL) "involves planning an intervention for engagement, responses, and representation of materials that will be inclusive of all students" (Browder et al, 2014). In Coyne's (2012) study, teachers following UDL had students with significant disabilities using e-books during reading instruction. The students' passage comprehension showed a statistically significant increase.

In the area of reading, studies have shown strong evidence for using read-alouds to increase comprehension and graphic organizers for summarization of key details (Browder et al, 2014). In the area of math, the use of graphic organizers and manipulatives, along with familiar stories has shown increased computation ability (Browder et al., 2012). In the area of science, peer tutors, graphic organizers and the process of systematic instruction, students have shown progress in learning concepts (Browder et al., 2014) and especially with learning academic vocabulary through time delay (Browder et al., 2009).

Parent Expectations and Involvement

The third challenge to IDEA is parent expectations and involvement. As mandated by law, parents are to be partners with school systems in the development and process of the child's IEP, yet how school systems interpret this mandated partnership and participation does not always align with parents' interpretation, including their expectations and involvement. This section will include a discussion on parental choice, stress, advocacy, family partnerships and conflicts to parent expectations and involvement.

Parental choice

As IDEA mandates parent involvement in IEP planning and process, it would seem parents have a choice in educational settings, including the type of school, classroom and educational services. The idea is that when parents are given a choice of schools, they will shop around, gather information about quality and choose from a selection of alternatives to their current option (Schneider et al., 1998). “Disparities in differences of parents’ resources, involvement, and cognitive abilities are particular concerns when considering how parents will play an expanded role in choosing schools” (Schneider et al., 1998, p. 490). The process parents go through when choosing a school starts with first determining a set of preferences. Then they gather information about alternative schools. After, they make trade-offs between their choices. Next they monitor each school’s performance. Finally, they make sure their choice was good given their preferences.

Often parents are forced to choose a certain educational setting for their child, instead of having a true choice. The reality is budgets and predetermined ideas shape the options. This idealized notion of choice is far from reality, especially for parents of students with significant disabilities. Kruger and colleagues (2009) call this a “forced choice”. Being forced to make a choice that one does not fully support or possibly understand can cause undue stress.

Stress

Parents of children with significant disabilities experience greater stress than do parents of non-disabled children (Hayes & Watson, 2013; Oelofsen & Richardson, 2006; Webster et al., 2008). Burke, Chan, & Neece (2017) identified several factors that could intensify the stress level, including IEP meetings, which are often deficit-based and could include a refusal of services for the child’s special education; relationships with school personnel; dissatisfaction with the child’s special education, along with some parents having an inability to understand and enforce parental rights; and advocacy, where mothers are often the child’s only advocate, lacking the support of shared responsibility (Burke & Hodapp, 2016). Moreover, Wang and colleagues (2004) reported advocacy in general created conflict and stress. For example, mothers of children with intellectual disabilities experienced greater levels of stress when engaging in any type advocacy, having a lack of relationship with school personnel, and feeling dissatisfaction with services (Burke & Hodapp, 2014).

Two factors were identified by parents who had less stress, including frequent communication with school personnel and school partnerships that were positive and respectful. Parents who had strong social support and/or low financial burden experienced less stress than did parents with low social support and high financial burdens (McConnell, Savage, & Breitkreuz, 2014). Further, those families with strong social supports and lower financial burdens experienced the most positive outcomes even with increased stressors of raising a child with a significant disability.

Angell, Stoner and Shelden (2009) conducted a study on mothers of children with disabilities and their trust of school personnel. They found many factors from parents and school personnel which either facilitated or inhibited trust. Factors that contribute to levels of trust include a parent’s disposition, their previous experiences with school, and their child’s level of communication and behaviors (Angell et al., 2009). Parents' disposition extended to how trusting parents tended to be in all aspects of their lives. Angell and colleagues found that until some incident broke the trust, the majority of parents inherently came to school trusting educational professionals and the school system in general.

The study found that mothers closely monitored their children's behavior to determine how the child was handling school (Angell et al., 2009). If the child was well adjusted, the mother was more likely to trust the school; however if the child was demonstrating challenging or dysregulated behaviors, the mother suspected something wrong which negatively impacted her trust in the school. In addition, shared decision-making was important to developing trust.

Advocacy

Advocacy is an area research shows causes increased stress for parents. The concept of advocacy has been around since biblical times, yet the actual term *advocacy* was not used in literature until around 1970. Early on in the disability field, it was described as speaking and acting on behalf of another person with passion to help address their needs (Wolfensberger, 1977). This definition holds true today. Parents have long advocated for their children's special education, leading movements to provide for rights and advancements in education for children with disabilities (Kirk, 1984). Lalvani and Hale (2015) posit there have been no meaningful changes to educational law in the last 40 years as it impacts parents' need to advocate. The need still remains! Yet, most parents engage in advocacy without training or a means of formal preparation (Krueger et al., 2019).

Factors for Advocacy

Parents of all racial and ethnic groups and socioeconomic status engage in advocacy (Trainor, 2010a). Parents who have a good understanding of their child's disability and parental rights along with strong social-communication skills were found to be more likely to advocate (Burke et al., 2018). Literature has shown several factors important for advocacy to be effective: positive relationships between parents and school personnel (Blue-Banning et al., 2004; Hess et al., 2006); school personnel's access to information and supportive IEP teams (Park et al., 2001);

parents' access to knowledge of special education law, such as rights, responsibilities and process (Leiter & Krauss, 2004). Moreover, parents with higher socioeconomic status showed increased advocacy than parents with lower socioeconomic status (Trainor, 2010a). Advocacy includes negotiating for services and supports. Parents were most successful with negotiations when they used their knowledge of special education law, remained focused on their child's needs, and were persistent (Rehm, 2002; Rehm & Rohr, 2002).

Barriers to Advocacy

Research has identified barriers to parents' ability to effectively advocate including readability of forms and language barriers. Studies found parents' rights and responsibilities handbooks were not written to be easily read by many parents, with 20% to 50% of the content being written at a college reading level (Fitzgerald & Watkins, 2006; Mandic, Rudd, Hehir, & Acevedo-Garcia, 2012). For context, the latest report from the Program for the International Assessment of Adult Competencies found 52% of Americans read at or below a fifth-grade reading level (Goodman et al., 2013). In addition, language barriers are also a factor for parents who are not fluent in English (Lian & Fontánez-Phelan, 2001). Socioeconomic status is both a factor and barrier to advocacy. For example, Trainor (2010a) found parents from low-socioeconomic backgrounds tended to defer to school personnel for decision-making, instead of advocating to be a decision-maker.

Advocacy involved mothers to maintain vigilance over their child's programming (Lalvani & Hale, 2015). Mothers' advocacy was effective when they became a "squeaky wheel"; speaking up with concerns and questions. Using this strategy led mothers to believe their children would not have been educated the way they preferred (i.e. inclusive) had they not spoken up persistently (Lalvani, 2012). Rehm et al., (2013) found that parents became burned out after years of conflict. Parents who were dissatisfied with their child's education due to lack of support from school personnel and lack of effective educational programming also reported being exhausted, frustrated and overwhelmed as a result.

Types of Advocacy

Researchers have identified different types of advocacy. Trainor (2010) identified four types of parent advocacy: 1) intuitive advocate, 2) disability expert, 3) strategist, and 4) agent for systemic change. The type used was often correlated with socioeconomic status and capital (cultural, social and economic). Some parents used only one type; usually those with low socioeconomic status and limited capital, while parents with higher socioeconomic status and more capital used more than one type.

Intuitive advocate. The intuitive advocate was a parent who saw themselves as the expert on their child and their needs in school. Intuitive advocacy was most often used by parents who did not have a deep understanding of the complexities of disability and special education and was often the only type of advocacy used; though parents who did have this knowledge also used intuitive advocacy, just to a lesser degree. This approach was not always the most effective, nor powerful, with parents often finding teachers to disregard their intuition, no matter the parent's socioeconomic status.

Disability expert. The disability expert was a parent who advocated by using their knowledge of disabilities. These parents became experts through learning from professionals outside of the school system, such as doctors, therapists and others in the field, including nationally recognized experts. They also read books, searched websites, participated in disability-specific organizations, attended workshops and conferences, and then shared their knowledge with school personnel. Disability expertise advocacy was most often used by parents of children with autism, no matter the socioeconomic status. This advocacy style often included using specific instructional language on IEPs, such as "discrete trial" (p. 41) and led to greater reported outcomes of successful advocacy. However, parents also experienced feelings of vulnerability regarding how much to disclose about their child's disability, as they did not want to encounter the teacher's deficit mindset, creating a barrier to relationship development. Although parents did not experience full connection with teachers, they were able to develop relationships with other parents who had children with a similar disability through support groups and networking. These relationships offered greater social support, knowledge gains around disability and increased confidence with advocacy.

Strategist. The strategist was a parent who advocated using their in-depth and technical knowledge of special education law, including policies, procedures, and rights. This parent understood their capacity to be a decision maker for all areas of their child's special education programming, including accommodations, placement and services. They realized the IEP was a legal document of the school's responsibility for their child's educational programming and monitored as such. The majority of parents who were strategist advocates were white and of middle or higher socioeconomic status. These parents were measured with their communication styles in order to support successful advocacy, believing that being demanding or holding school personnel responsible to implement their child's IEP would make parents dislikable. In spite of this apprehension, parents still frequently monitored their child's programming, with some parents who had economic capital also using legal references towards school personnel. One strategy used by these parents to mitigate being seen as demanding was to create a positive presence in the school through volunteering or stopping by to say hello and become familiar with school personnel.

Change agent. The change agent was a parent who felt it was their mission to impact change. They were acutely aware of the necessity to have cultural and social capital in order to effectively advocate for their child's programming, yet how this was unattainable for many parents. Therefore, they advocated for systemic change using their intricate understanding of special education and school systems' operations and devoting time to developing relationships with stakeholders. This group of parents described themselves as privileged with their healthy amount of cultural, social and economic capital; the latter being necessary for this type of advocacy.

Trainor also found that as parents increased their cultural and social capital, they found greater success with their advocacy efforts. She also determined that having capital was necessary and all types of advocacy (i.e. cultural, economic and social) must be applied in order to achieve some sort of equitable parent-school partnership. In addition, it was noted that the level of capital a parent has is not correlated with their level of power. Interestingly, parents of children with autism, regardless of their socioeconomic status, reported the highest amount of successful advocacy. Trainor suggested that the most effective advocacy was a result of parents having strong knowledge of their rights and IEP components along with relationships with stakeholders, including other parents of children with disabilities.

Rehm and colleagues (2013) identified three types of parent advocacy that were exhibited by most of the parents who were satisfied with their child's special education: 1) high-profile, 2) strategic, and 3) grateful-gratifier. These advocacy styles were developed after years of being in the school system.

High-profile. The first are high-profile parents whose style was to be highly involved and demanding with school personnel, wanting the best services for their child. These parents were considered to be “fighters”. High profile parents viewed themselves as the expert on their children and what would be most beneficial for their education. They felt their requests for services were crucial and also reasonable. When requests were not immediately granted, high-profile parents viewed school personnel as incompetent and blocking services. This viewpoint was sometimes perpetuated due to a history of denying services leading to parental feelings of animosity. As children get older and enter high school, it is common for them to receive fewer related services such as OT, PT, or speech-language therapy due to school personnel’s’ view of children not making progress as they age. High-profile parents reported denial of services to escalate the feelings of animosity, as they hoped their child would continue to make progress. High-profile parents tended to be white and have advanced degrees. Many were skilled at using legal counsel, which was viewed as a threat to the school district and therefore, worked in their favor to win negotiations, as districts did not want to incur the cost of a legal battle.

Strategic. The second style were the strategic parents who were measured and chose what to fight for and what to let go with the backing of research. These parents determined which goals were worth pursuing and advocated in an agreeable, yet assertive manner. Strategic parents often consulted with outside professionals. They were amenable to the legal rights and responsibilities, yet were persistent and always fully-engaged in decision-making. They expected nothing less than compliance on the part of the school district in terms of providing the services the parents requested. Though these parents were cooperative and preferred compromise over dissent with the school district, they were not averse to making threats or pursuing legal counsel if need be as a last resort. Strategic parents were well versed in special education law, including rights, responsibilities and IEP process, presenting themselves as equal partners in decision-making. They were measured in their advocacy attempts, yet, were expert negotiators. These parents developed high levels of trust with school personnel. Many of the strategic parents were white, had advanced degrees and worked in professional careers, though some mothers left their careers to care for their children. They were aware of their privilege and capital in relation to their advocacy.

Grateful-gratifier. The third style were the grateful-gratifier parents who developed trusting relationships with school personnel that were respectful and satisfying to both parties. These parents viewed school personnel as trustworthy and full of the best intentions to educate their child, often seeing school personnel as experts and developing high levels of trust. They focused on developing and maintaining relationships, along with following through with teacher recommendations. Grateful-gratifier parents were from all ethnic, racial and educational backgrounds and socioeconomic status. They tended to be parents who viewed their child's disability and abilities similar to school personnel and therefore were content with the services school personnel thought appropriate.

Systems and Advocacy

Most of the parental advocacy took place at the meso-level, with parents advocating to school personnel to impact their individual child's education. Some advocacy took place at the macro-level, with parents advocating legislatively to impact system changes, through policy and lobbying (Krueger et al., 2019).

Family Partnerships

Blue-Banning and colleagues (2004) determined the most important themes of effective collaborative family-professional partnership to be communication, commitment, equality, skills, trust, and respect. In their research, they determined parents want communication that is frequent, open, direct yet tactful, private and clear. It should include the child's positives and the challenges. The communication should be two-way and free from judgement.

Collaborative relationships include having openness in communication and the ability to share challenges as well as celebrations. Parents appreciate when teachers find and share resources and strategies. Many times parents take an active involvement and implement the strategies at home (Townsend, 2012). Zoints (2014) described parents' desire for training within schools on topics such as special education law and programming, advocacy and other services. A possible way to increase family partnerships with schools is when schools provide support or resources leading to supports during known challenging times such as major life events and transitions (Westling & Fox, 2009, as cited in Browder, et al).

Parent education programs strengthen families and improve parenting styles, which leads to greater outcomes for children (Jackson, Liang, Frydenberg, Higgins, & Murphy, 2016). By providing parent educational opportunities, school collaborative teams can support parents and improve relationships and outcomes for children with special needs. One school described by Serres and Simpson (2013), hosted an evening event for all parents, not just those with a child with a disability. The event included collaborative teams of the school social worker, counselors, educational diagnosticians, occupational and physical therapists, behavior specialists, school psychologist, and teachers. The event consisted of breakout sessions by experts on homework, pre-kindergarten preparation, ADHD, development of motor skills, and getting ready for intermediate school. Local businesses donated food and other items that increased attendance. Child care was offered for free by high school groups. The event began with an enjoyable opening of snacks, beverages, mingling and opening act and song. Parents attended two of their break out sessions of choice and completed evaluation sheets at the end. After the event, the parents expressed the desire to attend more sessions in the future. Low-income communities tend to have less attendance at extracurricular events, except for when the children are performing. This event was relatively well attended. An unintended benefit was that it also supported camaraderie of school personnel by working together to support parents.

Parents expressed the need for administrators to have adequate training in special education and working with parents of children with disabilities, and teachers to have quality training and education. In addition, paraprofessionals are often used as a support for students with significant disabilities. Therefore, it is necessary to provide training for paraprofessionals that is explicit in the areas of disabilities, content knowledge, effective teaching strategies and social skills, in order to increase their effectiveness and confidence in providing academic and functional skills instruction to students with significant disabilities (Browder et al., 2014). Parents also felt strongly about staff receiving sensitivity training on topics of Low Socioeconomic Status, communication with parents regarding disabilities and progress, participating in home visits and/or spending time in the school's neighborhoods, as well as how to advocate for children (Zoints, 2014). Parents expressed the desire for their child to be included in order to experience quality of life, in spite of the social and attitudinal barriers that are in place. In order for meaningful participation to occur, the following attributes have to be in place: choice, acceptance, safety, accessibility, and accommodation. These attributes were essential to creating a sense of trust in environments where participation occurs (Woodgate, Edwards, & Ripat, 2012). Without trust, a parent's guard goes up.

Trust

Trust is a leading factor in effective collaborative family-professional partnerships and depends on the communication a parent has with the school (Blue-Banning et al., 2004). Hoy and

Tschannen-Moran (1999) defined trust as “an individual’s or group’s willingness to be vulnerable to another party based on the confidence that the latter party is benevolent, reliable, competent, honest and open” (p. 189). Their study found a fully trusting relationship must contain all of these aspects of trust.

Parents of children with significant disabilities often share common experiences with the school and special education system. Many of those experiences are negative, but a few can be positive once trust is built with a key staff member. The quality of interactions between family and school are relevant to the child’s outcomes (O’Connor, Howell-Meurs, Kvalsvig, & Goldfeld, 2014). Parent levels of satisfaction are closely related to feelings of respect from school personnel. When parents feel a high level of rapport and feelings of kinship, they prefer that staff member to work with the child. Further, parents want to feel like a team member with the special education staff and have a true collaborative relationship (Zoints, 2014; Townsend, 2012).

Factors for trust. Angell, Stoner and Shelden (2009) conducted a study on mothers of children with disabilities and their trust of school personnel. They found many factors from parents and school personnel which either facilitated or inhibited trust. Factors that contribute to levels of trust include a parent’s disposition, their previous experiences with school, and their child’s level of communication and behaviors (Angell, Stoner, & Shelden, 2009). Parents' disposition extended to how trusting parents tended to be in all aspects of their lives. Angell and colleagues found that until some incident broke the trust, the majority of parents inherently came to school trusting educational professionals and the school system in general. Interestingly, Stoner and Angell (2006) found that mothers of children with autism who had to intensify their negotiations for their child's access and monitoring of their child's education had low trust with school personnel.

It was found that mothers closely monitored their children's behavior to determine how the child was handling school. If the child was well adjusted, the mother was more likely to trust the school; however if the child was demonstrating challenging or dysregulated behaviors, the mother suspected something wrong which negatively impacted her trust in the school. In addition, shared decision-making was important to developing trust.

A teacher's characteristics impacted mothers' trust. These characteristics include the notion of authentic caring which is defined as exhibiting behaviors that support student learning, being accepting of and empowering parents; communication with parents, which is defined as honest, frequent and prompt whenever there was a problem; and knowledge about the child's disability and needs (Angell et al., 2009). As it pertains to trust, communication was found to be of utmost importance. Lake and Billingsley (2000) identified when teachers demonstrated strong communication skills with parents, it facilitated favorable and constructive working relationships between the two parties. In addition, mothers value a teacher's knowledge and training (Elbaum et al., 2016). Mothers' perception of a teacher's competence impacted their trust in the relationship (Angell et al., 2009).

Mothers felt that the school administrator was the main person at the school who could increase or decrease their trust (Shelden et al., 2010). For example, when administrators showed a genuine interest in their child, were available and communicated with mothers, trust increased. On the other hand, when administrators were inaccessible, did not show an interest in children with disabilities, or were inflexible, trust was eroded. Mothers also felt that when school services were not implemented appropriately and the IEP was not followed, they had to increase their monitoring of services and at some points involve legal counsel through due process, leading to a loss of trust.

Factors for distrust. Angell and colleagues (2009) discovered that several issues in school caused mothers to distrust. These included school personnel's failure to: 1) understand the child's disability; 2) address child's needs through accommodations; 3) follow through with recommendations; 4) maintain confidentiality; 5) effectively communicate; and 6) implement the student's IEP. In addition, school personnel's lack of training and flexibility affected trust. Collaboration was also an important factor for a trusting relationship, as it was imperative to the child's success. When collaboration was missing, trust was lessened. Barriers to effective collaboration and instead mothers and schools viewing each other as adversaries more so than partners have been noted in the literature for decades (Covert, 1995; Lalvani & Hale, 2015; National Council on Disabilities, 1989; Rehm et al., 2013; Stoner et al., 2005; Wang et al., 2004; Woods et al., 2018). Furthermore, mothers distrusted schools due to their suspicion that "masked issues" (Lake & Billingsley, 2000, p. 246), such as budgetary constraints were the reason for their child's lack of services or supports, though schools were not legally able to say that was a factor. It is true that there is a lack of resources needed in order to meet educational goals. However, the bitterness between the parties is due to schools' lack of transparency with parents and not solely a result of lack of funds (Kotler, 2014). If schools would be honest and transparent with parents about the services required to meet a child's goals as intended by IDEA, there may be less contention between the parties and greater trust due to vulnerability and openness (Hoy & Tschannen-Moran, 1999). Importantly, Kotler (2014) implied that without trust between parents and schools, the goals of IDEA can never be achieved, as trust between the stakeholders was at the core of the goals of the Act. In order to reestablish the trust, each party has to believe the other is operating with the best intentions; although this is virtually impossible without transparency and full-disclosure (Kotler, 2014).

Leiter and Krauss (2004) did a study on parents' satisfaction around their child's special education services. They found the majority of parents with children in special education were satisfied with their child's IEP and services. However, a small group of parents whose children tended to have more significant disabilities were dissatisfied with the IEP and services. In addition, it was determined that parents' satisfaction with their child's special education was related to their expectations. Parents with high expectations tended to be less satisfied with their child's services, whereas parents with lower expectations tended to be more satisfied. Further, parents with older children reported the most dissatisfaction, leading to believe that younger children with disabilities are provided more services at a higher level, than older children with disabilities.

In summary, school personnel who showed an interest in children with disabilities and their parents, implemented the child's IEP, were supportive and focused on the children's needs, while maintaining transparency and open communication, helped to support a trusting relationship with parents.

Conflicts with Parent Expectations and Involvement

The literature asserts parents have long struggled with partnerships with school personnel, with parents often feeling disenfranchised, confused and frustrated by their interactions with staff (Sauer, 2007; Soodak & Erwin, 2000; Wang et al., 2004). Parents have felt at odds with their child's IEP team for decades, often feeling alienated from the system and in opposition to the beliefs and opinions of school personnel (Erwin & Soodak, 1995; Lalvani, 2012; Wang et al., 2004).

Many mothers had negative experiences with the school and special education system. Townsend's study (2012) highlighted the challenges for mothers within the system. School personnel viewed mothers as uneducated, not involved and low-income. Mothers felt school personnel preferred their own "privileged knowledge" (Hetherington, 2012, p. 192) to the mother's expert knowledge of their children. Moreover, Trainor (2010) identified mothers' expertise on their children was not always valued and respected by school personnel.

A mother of a child with a disability has to put their emotions aside, gather strength, and rise above to ensure that their child is receiving the supports necessary. Mothers also have to become educated on the disability so they can support their child according to research and as it pertains to their disability and their development (Burgess, Harris-Britt, Boyer & Marks-Frey, 2014). Mothers have experienced the challenge of parenting a child with a significant disability along with the challenge of navigating the special education system as an advocate for their child. "Understanding and negotiating the special education labyrinth, complicated by the intersecting oppressions of race and autism, leads to differing levels of maternal agency targeted toward the primary goal of having the children's needs met" (Hetherington, 2012**,** p. 189).

Power dynamics between IEP team members are a factor in determining plan outcomes (Martin et al, 2006; Ruppar & Gaffney, 2011), as research has shown many team members do not demonstrate meaningful participation in the decisions that are made, instead deferring to the meeting leader as the expert (Martin et al., 2006; Ruppar & Gaffney, 2011). Ruppar & Gaffney (2011) found that even when a teacher felt strongly about a particular issue, they deferred to the school psychologist as the leader. Though an IEP is supposed to be drafted at a meeting by the entire team, long standing culture promotes school staff team members to meet privately before the meeting to draft an IEP in order to come prepared to the meeting (Ruppar & Gaffney, 2011;

Trainor, 2010). This leaves the parents at an immediate disadvantage and power differential. Even if one or more members of an IEP team support a different decision for a student's plan, bureaucratic routines and school practices lessen the capabilities of which team members can make decisions about placement (Mehan et al., 1986). Due to an unequal distribution of power between school personnel and parents, Harry & Klingner (2006) found parents' attempts to negotiate were often ignored leading to improper decisions regarding placement and services. It should be noted that historically, parents have used their power to advocate and change the educational system (Turnbull & Turnbull, 2001). However, it is not uncommon for parents to have to continuously "fight" for services and their child's education due to the embedded culture of professional dominance. Parents are not equal partners and decision-makers--school personnel are the decision-makers (Lalvani & Hale, 2015). School personnel hold the power to determine parental involvement (Harry, 1992), such as when and how much will be allowed.

Parents want to be partners with school personnel to help their child be respected, meet goals and have successful outcomes. Turnbull & Turnbull (2015) discovered parents want school personnel to acknowledge parents are the bedrock for their children and therefore to have empathy and compassion, leading to them and their children being treated with dignity. Parents want school personnel to recognize the importance of children with disabilities having equitable opportunities to learn skills for their futures, leading to independence and participation in their communities.

It is important to note that a parent's ability and willingness to be involved in their child's education and partner with the school system is impacted by something called capital. This includes the parents' knowledge, skills, relationships and financial means.

Capital

In 1974, Pierre Bourdieu identified three forms of capital: cultural, economic and social. Cultural capital refers to one's learned behavior, knowledge and skills, such as educational qualification, their social class and material objects, such as books, technology and clothing--often linked to one’s socioeconomic status. Cultural capital is passed from one generation to the next and determines one’s position in society; however, this position is dependent on other’s position in the same space. For example, when interacting with schools, parents tend to have a lower position of power than do school administrators. Cultural capital is tied to economic and social capital. Economic capital is the readily available material assets such as one’s financial resources and owned property. Social capital is the networks and relationships one has achieved by putting in the effort; it is not inherited or handed down. It is often connected to one’s social class. Bourdieu (1974) claimed that people who have a lot of different types of capital have greater access to other resources. In other words, mothers who have multiple sources of capital can obtain more resources than mothers who do not have these sources of capital. Trainor (2010a) claimed parents who have all three types of capital are more likely to have quality education for their children. For example, mothers have been shown to use their cultural and economic capital to learn about placements and best-practices, special education law and how to become an effective advocate (Lalvani & Hale, 2015). Some mothers even used their capital to obtain the diagnoses they wanted, leading to specific selection of services (Lalvani & Hale, 2015; Trainor, 2010b).

A mother’s advocacy is connected with her capital. According to Simplican et al. (2015), mothers’ advocacy has been a strong influencer of their children’s inclusion in general education. However, Trainor (2010a) posits mothers’ involvement in the IEP “requires a complicated appropriation of both knowledge and dispositions (i.e., cultural capital) and relationships with school personnel and others (i.e., social capital)" (p. 247). Ruppar et al. (2017) surmise that mothers do not have the ingress to cultural and social capital necessary to productively participate in an IEP meeting. Ong-Dean (2009) also found parents must have high levels of cultural and economic capital to effectively dispute school decision-makers, thereby excluding parents from marginalized groups and those with lower socioeconomic status. For example, Lalvani (2012) found middle class mothers were better able to advocate for specific services than mothers in a lower socioeconomic status. In addition, when mothers learned and used complex language of disability and professional jargon, such as *applied behavior analysis*, they were more successful in their advocacy attempts for access to services (Trainor, 2010b).

Connell (2016) found that knowledge comes from experience. Mothers who were able to interact with and develop relationships with other mothers of children with disabilities had access to "hidden cultural capital" (Trainor, 2010b, p. 259) which offered them gained knowledge in how to navigate their child's special education, though even with this increased capital, they still encountered barriers to effective outcomes, such as school personnel dismissing their knowledge. Horvat et al. (2003) assert this ability to network with other mothers regarding school challenges is a middle class phenomenon; one that is not readily accessible to mothers with lower socioeconomic status.

Bourdieu positions that unequal access to capital leads to inequities in power. Findings show mothers can feel disempowered during IEP decision-making when there is a differential between mothers who may not have much cultural and social capital and the other IEP team members who may have more social capital (Trainor, 2010b). This disempowerment can be explained by the mesosystem in Bronfenbrenner's Ecological Systems theory (1977).

Lake and Billingsley (2000) found both mothers and schools have bases of power which shift back and forth between each party. Their study discovered mothers use their power (capital) to achieve what they want, as noted by a mediator participant “A parent who will take you to the cleaners at any cost is in a very powerful position” (p. 249). Likewise, studies have shown that parents who have capital, will seek outside resources to educate their children and not depend fully on public school options to meet their child’s needs; in contrast, parents without capital “will be forced to lobby the schools and elected officials to equalize public and private education” (Kotler, 2014). Regardless of the power and capital mothers have, the system is inherently resistant to honoring mothers’ requests (Lalvani & Hale, 2015). As such, Trainor (2010b) asserts that school personnel have a deeper understanding of the specifics and technical language of IDEA to benefit and support their decisions, whereas parents do not, creating an imbalance of power.

Summary

In conclusion, students with the most significant disabilities, including those who require the most supports, do not have much representation in the literature (Browder et al., 2014). There is limited research on how educational systems and mothers of children with significant disabilities work together, or not, to set goals and create opportunities to learn for the child. Although federal law mandates the participation of parents, effective participation has not been found. In addition, federal law dictates how students should be placed based on where their IEP goals can best be met, yet school districts continue to place students based on other factors unrelated to their IEP goals. While parents may desire a specific placement, services or programming for their child, their advocacy efforts create stress and impact the partnerships they may have with the school system. Further, parents’ capital plays a significant role in their interactions, directly impacting their advocacy efforts and abilities. The longitudinal perspective of this collaboration, along with the voice of parents of children with significant disabilities and their experiences are historically absent from the literature. Therefore, the study sought to determine how mothers of children with significant disabilities navigate their child’s special education. The next chapter will present the methodology of this study.

Chapter 3

Methodology

This was a qualitative study seeking to answer the research question, *How do mothers of children with significant disabilities navigate the education of their children from diagnosis through age 21*? According to Merriam and Tisdell (2016), “the purposes of qualitative research are to achieve an understanding of how people make sense out of their lives, delineate the process (rather than an outcome or product) of meaning-making, and describe how people interpret what they experience” (p.15). The term qualitative research has only been around for about fifty years, though this type of inquiry has been documented for a century or so. I chose this type of research methodology, because I was looking to understand mothers’ experiences with their child’s special education.

For this study, I used a phenomenological approach. Phenomenology is the study of how one experiences something. It is based on Husserl, a German philosopher, who is considered to be the original creator of phenomenology, though it has since evolved into being the way I describe it today. I adopted this approach, because as humans, we experience the same thing in unique ways, therefore our perceptions of our experience are not the same. For example, three of the mothers in my study were parents in the same school district and two in the same high school, though their experiences and perceptions were completely different. Studying their experiences as they were described is phenomenology.

Specifically, this study initially followed Moustakas's (1994) transcendental phenomenology, which removes any ideas that could be considered conjecture and presumed, forced me to bracket out my experiences as a former special educator, and focus entirely on the bare descriptions of the participants’ experiences. This approach and population sample allowed me to understand the experiences of mothers of children with significant disabilities, while also allowing each mother to have a voice, share her story and perhaps reflect on her choices through a continuum of the medical and social models of disability along with the frameworks of Ecological Systems Theory and educational stages. However, this approach was not the final one.

While I started out attempting to use transcendental phenomenology, bracketing my bias by writing down my beliefs and preconceptions, making them visible and increasing self-awareness, I know that who I am and what I have experienced directly impacts my thought process and analysis, as Charmaz (2008) described with constructionism. Even with attempting to have a "clean slate" as one would with transcendental phenomenology, I found I could not be completely impartial. Thus, a constructionist approach was also applied to this study. Constructionism is the belief that one's knowledge is subjective; based on one's experienced reality and interactions with others, and is driven by the researcher's values and biases, and therefore might conflict with impartiality (Charmaz, 2008; Kawulich, 2012). The focus of this study was on the experiences of mothers of children with significant disabilities. Therefore, I took into account the multiple realities of mothers through the method of interviewing to hear their stories. Applying a constructionist approach within this qualitative method of inquiry allowed my knowledge, perspectives and positions to reflect in the data collection and analysis, while ensuring the mothers' voices and views were essential to the data analysis and reporting (Charmaz, 2008). This type of investigation allowed for the subtleties of human experience to float to the surface and deepen the understanding of the essence of the experience by showcasing the complexity of each mother's unique situation.

Constructionism is similar to interpretivism, though interpretivism is much more focused on the researcher's subjectivity during analysis. So, as I went along, my approach morphed somewhat into interpretivism. I initially thought I was following transcendental phenomenology, with seeking to find the mothers demonstrating a shift of mindset, as had happened in the pilot study. However, as the interviews completed, the research became more about connecting with these participants over their experiences, of which I had shared similar experiences being a special education teacher and advocating for my families, which led to the shift of approach--starting out thinking one will solve a hypothesis versus letting the research flow where it does. This interpretive approach is about using social constructs, cultural norms and relationships as part of the analysis. I could not completely bracket my beliefs with a clean-slate. I now believe that to be impossible, as our experiences shape us to who we are. As a result, it came to be that a blend of constructionism and interpretivism was the final theoretical stance used for this study.

This study followed a retrospective interview approach, which consists of individual interviews of people who have firsthand knowledge of their own experience; it provides a way to understand past characteristics. This approach was important to the study as I sought to determine mothers' experiences over fifteen or more years of their child's schooling. Using this approach allowed the mothers to reflect back on the early years of their child's education. With this approach, I had to prepare and practice the interview questions so I could gain as much benefit as possible from this method (Gant, 1977). I want to note that Groenewald & Bhana (2015) caution that a limitation of using retrospective research is related to the truthfulness and authenticity of the data provided by the participants, which could pose challenges as it may be difficult for participants to accurately recall events from many years prior. This challenge was experienced by participants in my study.

Data Collection Methods

Participants

The criteria for participants in this project was: 1) Be a mother of a child with an identified significant disability, defined as children with autism, developmental disabilities, intellectual disabilities, and/or multiple disabilities; 2) Child must be between the ages of 16 and 26 years old; 3) Live in Metro Milwaukee area.

Six mothers of children with significant disabilities were interviewed regarding their experiences in negotiating access to, involvement in, and progress through the education of their child. The sample focused on mothers with young adult children in an effort to interpret the shift of mindset, from early childhood through transition from school to adulthood. Participants signed an informed consent form, detailing the potential risks and benefits, and noting voluntary participation. Each participant was informed of her ability to discontinue participation at any time and to have her data removed from the study.

Recruitment

I used word-of-mouth and networking to connect with possible participants. This method was chosen as it was convenient and I felt the least intrusive way to contact mothers. I assumed that mothers would be more apt to be willing to participate in my study if they had some connection to me who could reference my credentials and qualities. Being caring, conscientious, compassionate, respectful, approachable and trustworthy are qualities which I embody. These are some of the qualities Patel and colleagues (2003) affirmed to support a researcher during the recruitment process.

I had some friends and acquaintances with children with disabilities that are well connected in the community, which helped me with snowball sampling, so “when viewed critically, this popular sampling method can generate a unique type of social knowledge—knowledge which is emergent, political and interactional" (Noy, 2008, p. 327). Two of the mothers knew each other from their children being in class together in high school. Two of the mothers met through a mutual friend and had play dates with their children. The other mothers did not know each other.

Mothers were recruited via email after initial interest, then interviews were scheduled (see Appendix A). A limitation of this recruitment method was that the participant group was selected from the networks within my network; therefore, the potential participants were likely reduced to certain demographics, lessening the diversity of the sample. Another limitation is that email may have not been the most effective method for recruitment. For example, I emailed several times with one mother, but never was able to obtain her phone number, which could have been a better method of connection with her, and consequently we were not able to conduct an interview in the time frame allotted.

Participant Characteristics

I interviewed six mothers of children with significant disabilities. All the mothers were white, had earned bachelor degrees and identified as middle or upper middle class. Three of the mothers worked outside the home and the other three mothers were homemakers. The children were diagnosed with either autism, Down Syndrome or a developmental and intellectual disability and ranged in age from 17 to 25 years old.

Angela's child, Max, has autism and still attends high school. Angela's experience with Max's education was challenging from the beginning. Her most positive years were while Max was in middle school.

Christine’s child, Hannah, has Down Syndrome and has completed high school. Christine’s experience was tolerable through elementary school. Middle school and high school were challenging times in a failed attempt for appropriate, inclusive education.

Kim’s child, Mariah, has Down Syndrome and still attends high school. Throughout Kim’s experience with her child’s education, it has been a challenge for appropriate education. She has always felt a disconnect between her and the school system.

Lisa’s child, Nicole, has autism and an intellectual disability and has completed high school. Throughout Lisa’s experience with her child’s education, it has been a fight for appropriate education.

Mary’s child, Rachel, has developmental and intellectual disabilities and still attends high school, in a transition program. Mary’s experience with her child’s education was positive until Rachel’s junior year of high school.

Susan’s child, Kate, has autism and has completed high school. Throughout Susan’s experience with her child’s education, it has been a struggle to achieve partnership and secure what she considered appropriate, individualized education.

Procedures

Interview Protocol

Interviews were semi-structured and conducted with each participant lasting at least 60 minutes, with some interviews lasting two and a half hours. The interviews were conducted in person and at a location of the participant’s choice: their home, a coffee shop, library or other location of their comfort and preference. Most of the participants chose a coffee shop for the interview. One participant chose her place of work since he is a teacher and wanted to meet during her prep time, as it was easier for her to meet during the work day than after work or on the weekends. According to Swaminathan and Mulvihill (2019), place of interview needs to be taken into consideration when analyzing the data, as the site can be impactful. I do not feel this interview was qualitatively different than the interviews conducted in coffee shops. This interview may have had more of a time limit than other interviews due to her having the designated prep time and an incident at the end of the interview where a scuffle and vandalism in the bathroom next to her office had to be addressed. Since we were at the end of the interview at that time, I do not feel this incident negatively impacted the data.

If further clarification was needed, participants were told of a possible second interview, though none of these required a formal second interview and instead a follow-up email was sufficient. Interviews were semi-structured and audio-recorded with the VoiceMemo app on my iPad, which was protected with passcode and fingerprint-recognition software for security purposes. If a participant had declined to be audio-recorded, detailed documents would have been taken in place.

Questions were designed based on focused life histories in a retrospective manner using the framework of stages and transitions as a timeline, along with five questions based off of Brookfield's Classroom Critical Incident Questionnaire (2017) to support participants' reflections (see Appendix C).

The procedure using a retrospective interview approach is comprised of the following stages:

1. Define the objectives of the inquiry by having a predetermined set of interview questions.
2. Determine preferred pool of participants
3. Contact participants
4. Conduct the interview using questions from stage 1

5. Analyze the results
6. Determine a conclusion. If the results do not answer the research questions, repeat stages 2-6 with necessary adjustments (Gant, 1977, p. 168)

Once each of the six interviews were completed, I attempted to transcribe through the Happy Scribe website, but errors occurred, therefore I manually transcribed all interviews verbatim into single Google Documents on the laptop. In addition to the audio-recording, I took notes both during the interviews and afterwards, to supplement the transcription. During the interviews, the notes comprised reminders for follow up questions or clarification. Afterwards, the notes consisted of things the mothers said that resonated with me, and ideas for potential themes and patterns.

Data Analysis

A thematic analysis was used for this study, which is a method for discovering, analyzing and describing patterns and themes found within data (Braun & Clarke, 2006). According to Braun and Clarke, thematic analysis can be implemented across many different epistemological and theoretical approaches, and it is particularly suitable for a constructionist model. This is because the belief is that an individual's knowledge is subjective, based on their experienced reality and interactions with others, and is driven by the researcher's values and biases, and therefore might conflict with impartiality. This aligns with the ecological perspective, sharing the notion that many systems impact an individual and a shift in one system creates changes, whether micro or macro in other systems.

After the interviews had been transcribed verbatim, each transcription was printed out and kept in a secure file cabinet at my home. I then read through each transcription as a preliminary review and completed a lifegrid (LG) for individual participants. LG is a retrospective data collection tool in qualitative research. The initial purpose of the LG is to facilitate and document discussion during semi-structured interviews; however, I used this tool during the data analysis by using the LG to organize the data and determine themes and patterns. In my proposal, I initially planned on using the LifeGrid as a tool to support the interviews. However, one of my committee members suggested using the LG as a tool for data analysis, instead of during the interviews as it may impact the flow of conversation. This was an expert suggestion for two reasons: 1) it certainly would have been cumbersome to use during the interviews and would have interrupted the natural flow of the conversation, and 2) I found the LG to be a supportive and effective tool for the analysis, helping to organize and make visible any themes and patterns that emerged.

I used the completed LG to analyze how life changes impacted a participant's life over a duration of time, including a deeper assessment of how these changes were experienced and managed by the participant (Groenewald & Bhana, 2015). The majority of studies in which LG has been used qualitatively were conducted for the field of healthcare (Berney & Blane, 2003; Parry, Thomson & Fowkes, 1999; Richardson et al., 2009); however, some researchers have used this tool to support interviews for relationship studies (Bell, 2005; Groenewald & Bhana, 2015).

The LG for this study was created to include important life events, stages and transitions, such as birth of child, diagnosis, Birth-to-3, and the transitions of birth-to-3 to early childhood, early childhood to elementary school, elementary school to middle school, middle school to high school, and high school to post-school and IEP process. The LG followed the interview questions posed for this study (see appendix D).

In addition to the LifeGrid, the content analysis had two coding cycles. The first cycle of coding involved once again reviewing interview transcripts. Then I developed a list of key statements about how the mothers navigated the education in order to facilitate opportunities to learn. This is referred to as horizonalization of the data by Creswell & Poth (2018), putting equal value to each piece of data and no piece is more important than another.

Next, I pulled out in vivo codes, defined as, “names that are exact words used by the participants” by Creswell & Poth (2018, p. 193). These codes were based on Bronfenbrenner’s Ecological Systems theory. For example I used the systems of micro- (student and teacher relationship), meso- (parent and teacher relationship), exo- (teacher preparation), and macro- (school culture and policy) as initial themes. Codes were determined by reading through the transcripts and making notes, then rereading, and writing down codes I determined in my mind. The codes were: administration, advice, advocate, blame/regret, capital, champion, communication, didn’t know what didn’t know, exhaustion, expectations, extracurriculars, fight/battle, flexibility, frustration, IEP, medical model, social model, IEP meetings, inclusion, involvement, lack of compassion/trust, lack of confidence with staff, lack of services offered, negotiation, options/choice, outdated services, parent as expert, parents’ needs, partnership/collaboration, relationship, special ed teacher unwillingness, teacher unwillingness, staff as expert, self-education of law, self-contained, staff, staff investment, training, transitions, trust, and value. The codes were then combined into categories: confidence with staff/staff investment/administration/flexibility; IEP; partnership/collaboration/communication/trust/champion; programming (inclusion, self-contained, extracurricular); negotiation/advocacy/involvement/frustration; capital; and advice. These categories were then combined to become the three major themes: advocacy, capital, and trust.

In the second coding cycle, I again reviewed each transcription and noted important quotes that popped out during the coding phase. The data were analyzed using Creswell and Poth's method of reducing the information into significant statements or quotes and combining the statements into themes (2018, p. 78), marking in each document as I went along. I then created Google Docs for each initial theme and began to organize the quotes. I noted how many of the mothers were in each theme, which helped to prioritize each theme's popularity. Initially, there were upwards of twenty micro themes. To support reliability, a second researcher reviewed the transcriptions looking for themes. After conferencing and reviewing with this researcher, the microthemes were combined into three major themes. The final major three themes emerged to be 1) trust, 2) advocacy, and 3) capital.

After the major themes were determined during the coding cycles, I reviewed the quotes to make sure they were in the proper theme, with some quotes being in multiple themes. Next, I went through each theme and organized it by the two theoretical frameworks. First, I organized each theme into Bronfenbrenner's Ecological Systems and then I organized each theme into the six educational stages all using Google Docs, as this was an easy format to copy, cut, and paste from document to document. Each of the documents was organized into a folder on Google Drive.

In the second cycle, I looked for the intersection of the systems and stages, from the codes being in both frameworks. From there, I developed a textural description of mothers' experiences with quotes from their interviews. Next, I created a structural description, and described how the mothers navigated their child's education to obtain opportunities to learn. Finally, I combined both the textural and structural descriptions into a composite description. This description is the "essence of the experience", which is defined as what the participants experienced and how within the phenomenon (Creswell & Poth, 2018, p. 201). Tables were used to organize key strategies for navigation by theme and its intersection with each framework.

In an effort to check the quality of the data and initial conclusions, I sought to determine the credibility of the findings. I did this through using a process of peer debriefing, a term developed by Lincoln and Guba (1985). This process was used to discuss the study and findings with a couple of friends, not associated with the study or participants, seeking to pull out anything that might be implicit to only me. This method helped to generate questions and analysis from the perspective of the school systems. I also reflected on the data and my analysis, to determine if my biases were too strongly impacting the findings. I reviewed the analysis from the perspective of the school system and interpreted the mothers' experiences through the lens of a special educator. This reflexivity supported the credibility of my analysis through a process of differing perspective checks.

Procedures for Protecting Against Bias and Protecting Human Subjects

According to van Manen (1990), bracketing one's own experiences when analyzing a study's data is difficult and can lead to assumptions popping up; therefore it is better to make one's experiences, beliefs and biases explicit. My experiences of ten years as a practitioner of special education and four years as a supervisor of student teachers, along with having friends who have children with disabilities and hearing their challenges with special education led me to an interest in this phenomenon of how mothers navigate their child's special education and shaped my biases. However, I had to be extremely mindful to be aware of these and how they led me to interpret the findings. These biases included bias against teachers not individualizing for students; lack of training and unwillingness to seek training; low standards for students with disabilities and special education teachers; unwillingness to implement appropriate education for students with disabilities; schools stating they "do inclusion", yet it's simply a placement of a student with a disability somewhere in the classroom--usually at a back table doing something unrelated--or having a paraprofessional take notes for the student, while the student is not engaged in the lesson; administrators not understanding special education and therefore not being able to offer appropriate support to teachers; districts not partnering with parents; and schools using a "one size fits all" approach. As bracketing is difficult, I wrote the biases down and attempted to see the counter argument. I spoke with some former colleagues who are special educators to hear their perspectives and understand the challenges, including budgets and lack of time and qualified staff.

It has come to my understanding that at times parents may have unrealistic expectations of teachers and the school system. However, I was not able to fully bracket and overcome my own biases, as my experiences are part of who I am and impact my thinking and data analysis, as Charmaz (2008) explains with the constructionist approach.

After participating in and completing the CITI training and listening to Dr. Ryan Spellecy's presentation on ethics and IRB, I thought about the ethical considerations for the participants in the study. Due to the nature of the topic of children with significant disabilities and interviewing mothers about their experiences, there are risks involved. Though these risks would be considered minimal by many people, they are still risks and need to be disclosed. Mothers of children with significant disabilities have experienced highly emotional and physically demanding experiences from the time they found out their child had a disability to their present day. When interviewing mothers and asking questions related to these experiences, there was a risk of emotional distress. As a graduate research assistant, I interviewed some mothers of children with complex medical needs. Many of the mothers became very emotional and began to cry when asked about certain experiences; others became silent. This is a risk that was disclosed to the IRB and to participants through the Informed Consent document. There also was a potential risk of loss of privacy and confidentiality due to identifying factors being collected for the interviews. If this information was not protected and encrypted, it could become a breach of confidentiality.

During the interviews, mothers may have disclosed sensitive information that could be considered harmful to children, for example abuse or neglect. As a former mandated reporter, I had to determine what needed to be reported and what was something I would have to keep confidential. That information was not gathered through the CITI training, so I contacted the IRB committee to determine and was told that I did not need to report anything of this nature.

Protecting Confidentiality

The transcripts of this study remain confidential. No information was included in this study that might identify the participants. Confidentiality was protected through the use of pseudonyms for participants, their children, schools and staff. All audio-recordings were stored on a passcode and finger-print protected iPad. Electronic transcripts were stored on my passcode and finger-print protected laptop. All hardcopies of study documents, including signed consent forms, interview notes and transcripts, were locked in a file cabinet in my home office. These items remain secure, having only been seen by me and my dissertation chair. All audio-recordings will be deleted by November 30, 2020. Hard and electronic copies of study documents will be kept in secure locations for use in future studies.

The phenomenological qualitative methodology with a retrospective interview approach allowed me to gain insight into how mothers of children with significant disabilities navigate their child’s special education. The next chapter will detail the findings from the in depth data analysis that was conducted.

Chapter 4

Findings

The purpose of this qualitative study was to examine how mothers of children with significant disabilities navigate the education of their children from diagnosis through age 21. The first three chapters offered an introduction to the significance of the problem, a review of the literature and the methodological design that was utilized for this study. This chapter will present the findings from the analyzed data.

A qualitative study employing a retrospective phenomenological approach was conducted with data collected through interviews. Pseudonyms for the participants, their children, schools and individuals mentioned were created to ensure that all participants' identities were kept confidential.

The three frameworks that supported my data analysis were 1) the medical versus social model of disability, 2) Ecological Systems theory, and 3) educational stages/transitions. During the data analysis, it became clear that the medical model versus the social model of disability was not an indicator, as mothers did not demonstrate a shift of mindset. Mothers either started out in either the medical or social model and remained there, with the majority of mothers in the medical model; therefore, this framework will not be discussed in the findings. The Ecological Systems theory was strong. educational stages/transitions analysis showed that transitions were not an indicator as mothers did not present this framework to be of importance, though I sought to determine if transitions were part of the navigation. However, educational stages were an indicator and therefore, solely educational stages will be presented in this discussion of the findings.

Theoretical Frameworks

Bronfenbrenner's Ecological Systems theory provides a way to understand the impacts families and children face and provides a framework to support understanding their experiences, including mothers' navigation of their child's education. This theory explains how different environmental systems, such as home, family, teachers, school, IEP, and culture, influence how a child and family develop and interact within and between other systems. The five major systems in this theory include: micro-, meso-, exo-, macro- and chrono-. In relation to this study, the microsystem is the relationship and interaction between the child and his or her teacher or therapist, as perceived by the mothers. The mesosystem is the relationship between the microsystems, for example, the mother and the teacher or staff. This system also includes relationships between teachers. The exosystem is how outside environments or situations indirectly impact the child, such as a teacher's preparation and training or the decisions made by administrators, all indirectly impact a child. The macrosystem is how the culture or policies shape the experiences and expectations of an individual. A couple of examples include, a pervasive school culture around the education of children with disabilities, and how parents are received in a school.

Bronfenbrenner's Ecological Systems theory was a supporting framework for data analysis. During the first round of analysis, I read through the transcripts and marked each of the codes with a system (micro, meso, eco, macro, and chronological); however, nothing emerged within the chronological system and there was no data pertaining to the impact of life transitions (e.g., divorce, or significant death in the family). Therefore, this system will not be present in the findings. Then, each of the navigation strategies were matched with the systems during the second round of analysis. This framework with key strategies for navigation is shown in Tables 1, 3 and 5.

The second framework, educational stages, are the grade levels of education, including Birth-to-Three services, early childhood, elementary school, middle school, high school and transition services (i.e. ages 18-21). During the first round of analysis, I read through the transcripts and marked each of the codes with an educational stage. Then, each of the navigation strategies were matched with an educational stage during the second round of analysis. This framework provides a way to understand mother's experiences chronologically over the years of their child's education, including when and how they were navigating their child's education, as shown in Tables 2, 4 and 6.

In analyzing the interview data, three major themes emerged which will be discussed in this section. These themes were: 1) trust, 2) advocacy, and 3) capital. These three themes reflected what mothers' experiences taught them regarding what is necessary to influence the education of their children and helped them determine how to navigate relationships with school personnel and the parents of their children's peers, the system and programming decision making. Each theme will be presented along with its supporting sub-themes. Finally, the findings will explain what strategies mothers used to navigate their child's education and provide an answer to the research question. Within each theme, a summary of the key strategies mothers used to navigate their child's special education will be presented in a table as related to the frameworks of systems and educational stages, including first, the four systems (i.e., micro, meso, macro, exo) and second, the six educational stages (i.e. Birth-to-Three services, early childhood, elementary school, middle school, high school and transition services). It is important to note that not all themes were impacted by all four systems or all six educational stages.

Thematic Description

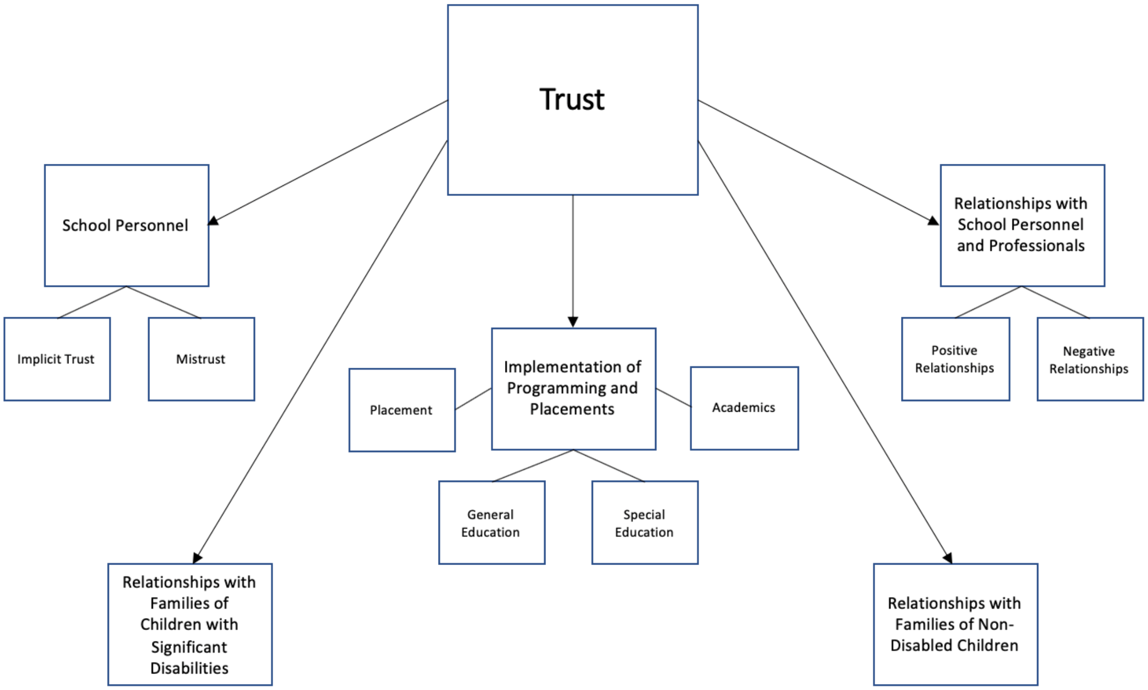
Three themes were identified from the findings: trust, advocacy and capital. These themes were strong across all mothers' data. First, I analyzed each of the themes and then I matched the strategies the mothers utilized for navigation in each theme with the two frameworks described above. Each theme will be presented below, including its connection with key strategies for navigation and each framework.

Trust

Trust was the most impactful of all the themes. This included sub-themes of school personnel, implementation of programming, relationships with school personnel and professionals, relationships with families of children with significant disabilities and relationships with families of non-disabled children as seen in Figure 5. The biggest area of trust was with school personnel. As I sought to determine how mothers navigate their child's special education, it became clear how important relationships and feelings towards implementation of programming were to their navigation.

FIGURE 5

Trust and Subthemes



Note. Concept map of trust theme and its subthemes. K. Wiseley, June 10, 2020.

School Personnel

Mothers indicated they began their child's school experience with what seemed to be implicit trust or took for granted a sense of hope in the system, believing that educational professionals were experts, had all the answers and would do the best for their child. School personnel included teachers, paraprofessionals, occupational therapists (OT), physical therapists (PT) and speech/language pathologists (SLP), administrators including principals, directors of special education and superintendents. This area of trust involved mothers' level of confidence with school personnel, the regarded level of school personnel's investment towards their children's education, and the apparent level of flexibility school personnel demonstrated towards working with the mothers and children. The subthemes are notions of implicit trust and mistrust, which will be explained below.

Implicit Trust

Mothers trusted school personnel due to lack of experience or not knowing any different and seeing personnel as experts with the best intentions for their children. Mary recalled, "And I think we trusted, because we didn't really know. This was all new ground for us." Mary homeschooled her older children, so consequently she did not have experience with public school, let alone special education services. When her daughter began public school, she was nervous and did not fully trust the programming. However, with communication, meetings and the rapport with a teacher Mary described as "grandmotherly", she quickly began to trust the teachers, seeing them as experts with the best intentions.

Likewise, Kim had a lack of experience and thought teachers had the best intentions for her child. She recollected, "But in the early years, I just went along with the program and the system. It just was what it was and I assumed everybody had our best interests in mind until I figured out I need to speak up." Kim trusted Mariah's teachers with what and how she thought they were teaching her child in general education, believing they had been trained and were the experts in educating her child.

> And at that point I trusted. Ok, you've had the training. I trust you then that you're going to do the work that you need to with her and there's a helper in there. There's always paras in there, um, so yeah, I always blindly trusted the school.

Later on, Kim found out that Mariah was sitting at a back table in the general education classroom and coloring, instead of receiving instruction, leading her to mistrust the system, which shifted the way Kim navigated her daughter's education.

Mistrust

Over time, the mothers learned that they needed to ask questions, verify, become more involved due to events that caused them to question this trust and begin to mistrust teachers and the system. Mothers felt teachers were not individualizing to help students meet goals and had suspicions of the IEP not being followed.

Susan's prior experiences with her older children's education caused the mistrust of the system, including school personnel. Therefore, when her daughter began attending school, Susan entered in with a lack of trust of school personnel. However, there was one teacher, whom Susan began to trust. This teacher worked well with her son. When Kate started kindergarten, Susan requested this teacher. Unfortunately, the teacher did not work with Kate leading to loss of Susan's trust, as she shared,

> I didn't trust anybody when it came to them doing what they said they were going to do. I had no experience with believing that they were going to do it…Kate hadn't met any of her goals, which I was used to--my kids never met any of their goals that were in their IEPs. And I'm not exaggerating. I had started getting this feeling about Kate's teacher, well what are you doing? She would always kind of be on my side. She wasn't doing anything.

Other mothers questioned if the teachers were actually working with their children and the notion of intent. Angela's experience started when her child was four years old. She expressed,

> ...you know, there was no aide for him, even though it was in the IEP. There was all this stuff in there that they never worked on. So I dropped out of my master's program because I would stop in there and Max would just be dee-dee-dee hanging out in this--it just was so unsupervised. There was no working on anything going on whatsoever. So, I

> dropped out of my master's program and I was like ok now I gotta come here all the time because you guys aren't doing any of this stuff. So, kind of walk back in there, was ridiculously anxiety ridden. And because all of the other process with them was always so hard and always like banging heads. Just hoping that they say what they're going to do. You have to count on them and they don't--whether they have intent to want to do a great job, or not, they don't know what they're doing and they don't seek help. So, and they still don't. My kid's a senior and they still don't. So, we just did everything outside of school.

It appeared to Angela that her son's IEP was not being followed, in addition to a lack of supervision, causing her anxiety and to withdraw from graduate school. The seemingly constant disagreement and her lack of trust and confidence with the teachers' skills, caused Angela strife and continued to erode her trust in the system.

Several of the mothers' children rarely met IEP goals, leading them to a mistrust of teachers and the system. Angela's son was consistently not meeting his IEP goals, which eroded Angela's trust of teachers diligently following her son's IEP. However, during one school year, she was allowed to have her son's ABA therapist support the teachers to offer tips and strategies for effectively working with Max. During that school year, there was accountability due to the frequent check-ins, data collection and rewriting of goals based on the data. Angela surmised,

> I mean, sure. Can you prove that it's not being followed? He just never hit goal and I'm like why doesn't he hit goal? I'm like last year we rewrote goals three times because we were making sure you were working on goals, but that was the year [ABA Therapist] was there.

When a new principal started and felt threatened by this mother's knowledge, advocacy and bringing in outside professionals which may have shown her lack of understanding and skill set, the therapist was no longer allowed to support in the school and Max went back to not meeting goals, which could be inferred there was a cessation of data collection and individualization. When data are being collected on a frequent basis--typically daily--and monitored weekly, it becomes clear to see a child's progress towards their benchmarks. If they are not meeting the benchmarks, there needs to be a shift in instruction, including scaffolding learning to build a foundation of skills. If a child is meeting benchmarks, then a shift to increase the challenge and add new benchmarks is warranted. In Max's case, when the therapist was involved in the school, writing and monitoring goals, Max was achieving. Once the therapist was banned from attending school with Max, Angela noticed Max was no longer meeting goals, leading her to believe there was a lack of data collection and progress monitoring.

There was a shared feeling that the general education teachers were not accountable for all students, including the students with disabilities being educated in their classrooms. Christine always wanted Hannah to be fully included with her non-disabled peers. She offered,

> I think teachers back then were feeling a little put upon. They weren't sure they were supposed to have kids with disabilities as their responsibility. They really felt like they--she's having a problem, she should go to the resource room and they should deal with it. So we had to work that out and it's like no, she's part of the community.

Teachers, however did not have the inclusive, "all students are my students and responsibility" mindset; therefore, when Hannah would demonstrate perceived behavioral challenges, the general education teacher would send her to the special education room, instead of effectively managing the behavior in the classroom. This would remove Hannah from her peers, effectively removing her access. Half of the mothers did not approve of their children losing access to non-disabled peers. For example, Lisa expressed her desire:

> That's what they did and we had the discussion. I wanted her to be around her peers as much as possible. So definitely phy ed, art, music for sure. In middle school, I want to say, I want to say in middle school she had smaller classes. She must have had a SPED teacher in middle school, you know, like in her own classroom. I know for a fact the [general education] math teacher and the English teacher are the exact same teacher as my son had. And I know that for a fact in middle school because I specifically asked for them.

Lisa trusted these two general education teachers to provide access for her daughter to the curriculum and peers in general education. This was granted because it was so important to Lisa that she dictated Nicole's schedule in order to provide access.

Mothers desired trusting relationships with school personnel, as Kim shared,

> The problem is there's all these nuances and new words and there's really just no nobody--I want somebody to be able to just lead me through the process and hold my hand and say, ok now we need to do this. Ok great. Let's do this. Kind of like I had in the beginning [during Birth-to-Three].

Kim desperately wanted and needed someone to help her through the nuances of special education, including what comes after high school during transition services. She only found that when Mariah first started services with Birth-to-Three. Since that educational stage, Kim was not able to find that person to walk her through each stage.

Implementation of Programming and Placements

Trust in the implementation of programs and placements emerged as a sub-theme. Mothers shared their feelings of trust or mistrust towards programming and placements. There was tension between what some mothers desired for their children’s access, while also not approving of how the general education programming was implemented for children with significant disabilities. Other mothers never wanted full access to general education and only experienced tension when the discussion of inclusion was presented. Several circumstances impacted mothers’ trust of the implementation of programming and placements. During elementary and middle school, half of mothers favored self-contained programming, feeling it was the safest placement for their children along with offering the specialized instruction they desired. The other half favored inclusive programming, wanting their children to be with non-disabled peers, though one mother was concerned with her child being a distraction in general education classes. The other mothers understood that inclusive programming was not implemented following research and evidence-based practices, as their children were sitting at a back table without appropriate and effective modifications and accommodations. When the child entered high school, all of the mothers favored self-contained programming, with a tension emerging from wanting an inclusive environment, but being unhappy with the current model, feeling it was again not following evidence-based practice. One mother experienced an abrupt change of programming, yet was not directly consulted nor informed of this change. All of these circumstances impacted mothers’ trust either positively or negatively. The sub-themes included placement, general education, special education, and academics. When mothers reflected their mistrust in programming, they spoke of placement, general education, special education and academics.

Placement

It was found that the majority of mothers preferred self-contained classroom and curriculum due to lack of trust in general education curriculum. Kim recounted,

> I feel like she spent most of the time in a classroom with the peers that had disabilities. And I was ok with that, just because I wanted her to be able to grow and be successful and I knew that things within the regular ed classroom maybe weren't what she--they weren't going to be supportive to what she--and my brother had grown up with a disability and back then they only had separate classrooms, and so to me that seemed like the norm.

Kim's brother had a disability and was educated in a self-contained classroom, so to her, this placement was the norm for children with significant disabilities. She did not trust that Mariah would get the support and education she needed in a general education classroom.

When asked how she felt about Nicole being in a self-contained environment after having been included in elementary school, Lisa offered, "Yup and I was fine with it. Because there was no way that she could have handled the traditional curriculum even with an aide." Although Lisa wanted her daughter to be included in general education as much as possible until middle school, it became clear to her that the curriculum and accommodations necessary for access to general education (i.e. having a para take notes for Nicole in class) were not what Lisa felt her child needed and could understand. At this point, she accepted the self-contained classroom and programming, feeling it was in line with her daughter's abilities.

Mary preferred a segregated environment, explaining,

> I would not be for isolate, but I would be for insulate. Isolate might be totally away from any other kids. I'm not necessarily for that, but let's insulate and make it appropriate

> where it’s safe and you know she’s safe. Where other kids, when they’re having reactions, but teachers know the kids who are more sensitive kids. I’ll put it that way. So, I think that was the case.

Mary trusted the segregated environment for the safety of her child, but also did not want complete isolation from non-disabled peers.

General Education

The mothers who desired an inclusive placement were challenged with building trust in the implementation of the general education programming and curriculum. They felt it was too challenging for their children, even with the school’s approved accommodations (e.g. a paraprofessional taking notes in the classroom while the child was relatively disengaged), or modifications (e.g. a coloring sheet somehow related to the topic being taught that day). When Kate started in middle school, Susan again wanted a specific special education curriculum and completely individualized and segregated program for her daughter; this desire may have intensified due to Susan’s understanding of general education (i.e. curriculum and instructional methods) for students with significant disabilities she had experienced with her older children. Therefore, having Kate included in general education was never discussed at her IEP meetings, as inclusive best practices were not regularly in place and Susan was completely against it due to her experiences that accommodations and modifications were not implemented in general education. She explained,

> They never even, it never even became a discussion point, maybe because it was so--I mean I think that it was, if that’s the way that it was going to be set up that there was a teacher and if you’re in the class, you’re in the class with your aide and you’re sitting in the back or you’re sitting in the front or you’re sitting at the side and you get pulled out

> for certain things. I think that, I think we all knew, so that really never became a question of whether that might be good for her or not. We knew it wouldn't be good for her and I know that's what they had. The adapting curriculum, the customizing curriculum, it did not exist.

When Mariah started attending a new school with inclusive programming, Kim was apprehensive and was told the general education teacher was a trained, expert reading teacher and therefore, it would be a great placement for her child. Kim observed,

> Mariah was in the regular ed classroom for reading. That was fourth grade. She did coloring in there, too. And I was assured that that teacher was very well trained and had all the experience and Mariah would just sit and color.

In this case, the "inclusion" was simply a placement in the general education setting where Mariah received no expert reading instruction. Mariah and other students with significant disabilities would sit at a back table with a paraprofessional and color. There were no accommodations and no modifications for her child, which made Kim distrust the school and personnel.

Mary was not informed of the changes to her daughter's programming and placement going from adaptive and self-contained to "inclusion" in general education classes. As a result, Mary felt she was not included in the decision-making process and was dismissed by the district decision-makers. Mary did not feel Rachel's new block schedule was appropriate and consulted with a trusted and knowledgeable friend. This friend reviewed Rachel's IEP and determined the new placement in general education was restrictive for Rachel's needs and therefore not in compliance with IDEA's Least Restrictive Environment. The change of programming without consultation and agreement from the parent eroded Mary's trust in the system. She stated,

> And then some changes started taking place when she was a sophomore. And then they had them in a little bit of regular classes and it was ok. And I'll tell you, the junior year, and this is where you're going to find my input on this, um, I know there's a lot of legal changes, but in her junior year, all of a sudden they are, except for living skills, and they still had the adaptive, shoot, I wish I could think what that's called--it's the technology classes basically; they had that still. Everything else went to regular programming. So, I'm going in and I see her schedule and I said, um, I'm looking at this and I said, this isn't adaptive. This is a regular ed class. She's in a regular history class and she's in a regular biology class and they said, well yeah, there'll be an assistant in with her. And I said we have 90 minute classes. I said, she functions at a six year old level. Would you put a six year old in this class? And the guidance counselor kind of laughed. I said that's what you're doing here. Um, and with the help of a friend who is a special ed teacher out of our district, she went through the IEP and she said because of some of the wording in the IEP, she goes, this is a restrictive environment. It's not a least restrictive environment. She goes, she should not be in this environment. So I really pushed…

Mary made a strong point of how students with enrichment needs receive specialized AP classes, whereas students with adaptive needs are included in general education classes and not receiving specially designed instruction for their needs. She wanted the adaptive classes in which her daughter seemed to thrive, while also enjoying her learning. Mary met with the Director of Special Education, recounting,

> I tried to say to the Special Ed Director, I said, you know, with our college bound kids, we have them take what kind of classes? AP, why? We have them take AP classes because they're preparing for what's ahead. I said, for our kids, what's ahead? They need

> life skills. They don't need geology or geometry. They don't need economics. They don't need that. That's a waste of their time. Their AP classes are like Mr. Nelson with the tech. They're learning things that are going to help them for the future. It kind of fell on deaf ears, but I made my case.

While Mary tried to implement change and be heard, she was not entirely successful in having her daughter's needs met. Angela also questioned how her son would be instructed in the general education classroom and the purpose for his placement. She wondered,

> I'm like how are you guys going to do this on a visual basis, or how is he going to learn anything? I'm like if you just want him sitting there so you can check the box for the fucking state--I'm like if you just need to check the box, we're not doing that. And you can write in there that I said no. I don't give a shit. That's going to be a shit show and every kid in there who wants to blame Max for being too loud for their bad grade, it's going to happen. So just, let's just not do it.

While Angela wanted Max to be included with his non-disabled peers as much as possible, she knew the general education classroom was not an appropriate placement, as his needs were such that he required an alternative environment in order to learn. When the school pushed for Max to be in general education classes, Angela questioned the purpose and benefit, calling out the school for focusing on numbers and reports instead of what is best for the child.

As their child moved through the educational stages, mothers began to see how complicated the general education curriculum became with advanced concepts in science and mathematics, along with English classes reading novels with mature themes. Mothers found their children did not understand the content and in one case, had nightmares, as Christine shared,

> And I have to say a lot of the regular ed teachers were very open to having kids in their class, but then they didn't know how to support them properly. The teacher was so happy and they even had a special ed teacher who worked with kids with LD more, um they were going to co-teach and so they let Hannah in and it was--for one the books were really scary. They dealt with, I'm trying to think, there was Romeo and Juliet which was--maybe that would have been ok, but then there was Holocaust book and then a slavery book and it just--Hannah was having nightmares about some of it. And they just weren't able to support it and they didn't know how to modify the curriculum so that Hannah got an appropriate amount of work to make it work. You'd get like ok you have to do these twenty questions. We cannot do twenty questions in a night. There was just no way. We can do three. That's the most. So we ended up not doing it.

Christine tried to focus on her daughter being educated in general education, but the themes were too mature and the expectations were not able to be met.

Special Education

General education was not the sole receiver of mistrust; many of the mothers did not trust the implementation of special education programming and curriculum content (i.e. life skills/functional academics). Christine and her husband dreamed of building their dream home on a large plot of land, though they knew the area's school district would not meet their expectations. Their plan was to send their children to parochial school, however, when Hannah was born, it became clear that she required services that only a public school could provide. Unfortunately, the public school district did not meet Christine's expectations with regard to her beliefs of how students with significant disabilities should receive instruction, including the type of curriculum and classroom location (e.g. special education classroom located in the basement of the school building away from non-disabled peers). In addition, when Christine asked about a more challenging curriculum leading to higher educational expectations for students with significant disabilities, school personnel were unable to offer any other options. This led Christine to assume a lack of training and experience on behalf of school personnel in working with students with significant disabilities. Due to Christine's inquiries, the school suggested open enrollment to another district. However, this offer was misplaced, as most school districts will not accept open enrollment of a child requiring extensive services, due to the cost. When it became clear that the school district was not able to meet Hannah's educational needs and goals, Christine and her husband decided to stay in their current district and put the building of their dream home on hold. Christine precluded,

> We have forty acres in Northern Westown County that we planned on building a house and living there. We knew it wasn't a very good school district, but nobody thinks they're going to have a child with a disability, so we just thought we'd use parochial schools and it'd be fine. Well, then Hannah came along and we had to check out the school district and it was terrible. She was two. And the kids with disabilities were in the basement. They didn't--they were all. It was a small school district. It's Northern Westown School District. It's a little tiny school district. All the kids were in one area of the school. They didn't eat lunch with anyone, they didn't do anything and 99% of them went into a sheltered workshop upon graduation. And the conversation was what if she can do better? And they didn't even know how to answer that. After a short conversation, they said, oh next year they're starting a new program and it's called Open Enrollment. You might want to look at open enrollment and see if you can get her into another school district--you might be happier.

This was one of Christine’s first experiences with widespread low expectations for a specific group of students. As she had high expectations for her daughter, she was disillusioned by the programming, isolated placement and seemingly lack of knowledge and understanding held by the district’s personnel.

Lisa experienced the challenge of the special education teachers being rigid and set in their ways. Nicole had learned how to do basic math operations of addition and subtraction using a method called TouchPoints, which is a series of dots assigned to each number and a pattern for counting the dots is learned to fade the need for dots on numbers and facilitate mathematical operations. Nicole's middle school teacher did not allow her to use this successful method, which caused stress, frustration and fueled Lisa’s distrust of the school and system, along with the continued feelings of fighting for her child’s appropriate education. Lisa recalled,

> Nicole was not allowed to use TouchPoint Math in middle school. They wouldn’t let her. Right. That was another fight. Why are we fighting this? TouchPoints really work for her. As a matter of fact that’s what she was doing well in, was math.

Once the child turned 18 and was eligible for transition services, mothers’ lack of trust with school personnel’s training and investment remained. Lisa shared an experience with her school district not knowing about popular transition service options.

> Project Search was told to us by another SPED parent. That wasn’t the school district calling me and telling me, ‘hey we have this great thing.’ That was another parent. I called the school district and said, ‘hey, I want to get her in Project Search.’ Their response was ‘what’s that?’ Fine, I’ll do that alone, too. Which I did.

Lisa found she had to take on finding and registering her daughter for transition services, as the school only offered basic job skills such as folding towels at the YMCA. Lisa had higher expectations for Nicole and did not trust the school to implement more challenging and appropriate transition job training.

Kim also did not trust the school personnel with her child's transition services. She said, "I think that that--the teacher can try all that he wants and DVR [Division of Vocational Rehabilitation] can try all they want, but nobody else is totally invested in this aspect of the process." Even though it is the teacher's responsibility to implement transition service planning and training, Kim did not trust the teacher's investment or skill set in this area.

Although many of the mothers were distrustful of the implementation of the special education programming, Mary found the curriculum in her daughter's self-contained classroom to be appropriate for Rachel's level of understanding and did not cause Rachel to feel frustrated. Mary preferred the adapted curriculum over the general education curriculum, which she felt was too challenging and caused her daughter to become frustrated and angry. She said,

> They'd have the basic living class and then they had--they would have adaptive Spanish, adaptive history, adaptive math. It was amazing. It was really good. So the Spanish, I mean, in adaptive Spanish, she actually learned Spanish. She learned counting to ten in Spanish. She learned hola, basic things. In history they did like I suppose a pilgrim stuff like that and in science they did basic biology. So it was all geared down to I'd say an elementary level kind of thing. And it was very cool.

Academics

As the children progressed through the grades, the mothers of children with Down Syndrome and Developmental Disabilities began to realize academics were not as great a priority as functional skills. This occurred late in middle school, when the focus in school also became more so about functional skills. At that point, as their children were not making progress in learning to read, the mothers began to demonstrate a feeling that life skills were more important. Interestingly, the children with autism had been learning functional skills at home during their years of intensive intervention upwards of 35 hours per week. Their mothers still wanted academics at the forefront, but expected differentiation in the curriculum to meet their children's unique needs. When this was not occurring in the schools, the mothers took it upon themselves to seek these services outside of the school system. Angela hired private therapists and psychologists to test and teach Max how to read. Susan purchased a curriculum and designed one-on-one programming for Kate at school, though she now regrets this induced isolation as it prevented her daughter from developing social skills. Susan recollected,

> They would do a lot of things and go in and out and do things, whereas Kate had her own like this is her desk area. It was cute. The para was instructed on, ok you spend this amount of time, you sit with Kate, you do this kind of curriculum, I mean, it really did remove Kate from those peers that she could have maybe had as peers. She still didn't have the skills, um, we were so busy working on other things--language, um, language, communication skills, still some academics. By then I recognized academics were not as important as what I had originally thought they were going to be. It was--I would do that differently. So my mistake was not letting--by insisting that the school follow the curriculum in the way that we wanted, it really um, prevented Kate then from being with her peers.

Susan purchased a curriculum and designed an individualized program for her daughter, where Kate worked one-on-one with a paraprofessional. Susan established that Kate was not involved with the curriculum the other students in the class were using and consequently did not have much interaction with her peers. Being a child with autism, social interactions do not come naturally for Kate. Susan came to regret that she focused so much on the academics and not on the social skills and interactions with peers and as a result, Kate missed out on these important opportunities to make friends and practice social skills with her peers.

Relationships with School Personnel and Professionals

A key component of navigation through the educational system was the mothers' attempt to develop rapport with teachers and administrators in an effort to improve or maintain the education of their child. Some mothers did this through their own offerings and others used outside professionals to support teachers' efforts with their children. Sub-themes of positive and negative relationships were found.

Positive Relationships

Initially, with Susan's development of an individualized program for Kate, the important component was having a trusting relationship with school personnel. Throughout most of Kate's years in school, Susan was integral in designing Kate's special education programming. In Kate's final year of early childhood, Susan designed a program specifically for her daughter with the help of the speech-language pathologist and an early childhood teacher. Susan trusted these staff members because she felt heard and respected by these professionals. Susan felt they were on her side and supported her desire and goals for Kate's education. Susan shared,

> I liked the speech pathologist so I trusted her. She was the same one that had been with Kate earlier. She was playing a role. I think I met somebody, somebody that they had in there and it might have been the teacher and I can't remember--I liked. They introduced that person to me. I felt like that person was with me on this. I felt like we had a partnership around Kate. I recognized there were a couple of other students that were coming in. I felt good about the fact that they heard me. I described what I was looking

> for Kate. They customized it for Kate. They brought other students in that ended up probably benefitting in some way. They had the experience of helping get her in to spend some time on a daily basis into the kindergarten class and I think that everybody saw that as a success and felt good about it, but it hadn't--again it was completely separate from--I mean the early childhood program as it was there.

When Kate started a new school for kindergarten, Susan entered into the school with her guard up. She was distrustful at the beginning due to her prior experiences with her older children in school. However, as teachers and staff began to explain their reasoning for the structure of the program, including what and how they were teaching, Susan slowly began to put her guard down and develop trust of the personnel. She explained,

> I was so distrustful by that time, that I didn't appreciate it at the beginning, but I came to love it. I came to learn it. So anyway, so I felt fairly ok going in there, because she's in this kindergarten class, it's half day, she's protected. She's taken care of…

Other mothers also developed trusting relationships with school personnel who were beneficial to their child's education. Kim experienced feelings of distrust when her daughter started middle school, due to the IEP not being followed and being lied to. She recalled,

> ...but at that point the IEP was so skewed, I think that there were things on there that she wasn't actually accomplishing and they said that she had accomplished, so then we had to back up the IEP so there was no showing of success. It just always looked like she was getting worse because we just kept downgrading the benchmarks, which was really--I felt like I had been duped. Like what the heck? You know. Because she still can't count 1-10 without skipping the number 8. [laughs] Yeah and that was hard. And so it's like when

> the new teacher came in it’s like, ‘we’re going to see change’, which we did. I mean, she grew leaps and bounds that year, which was really awesome to see.

Kim went from experiencing implicit trust at the beginning of her child’s education to experiencing distrust in a few short years as incidents caused her to question teachers’ intentions and abilities to teach Mariah. When the new middle school special education teacher was hired, she came with fresh ideas and the intention to work hard for her students in meeting their goals, which established a new sense of trust in Kim. A secure and trusting relationship was developed between Kim and this teacher as a result of daily communication and Mariah’s affection for her teacher.

Mary’s trust in Rachel’s first grade teacher was so strong that she and other parents asked for this teacher to transfer to second grade and continue to teach their children. She explained,

> Well, there was one particular teacher in first grade, who we absolutely adored. Absolutely adored. And actually there were--she was in a group with four, so she was very fortunate. There were four of them the same age, very similar abilities, which I understand is not very common. And all four of us really loved this first grade teacher and wanted them to, I can’t think of the term, but follow up to grade. Because they do do that sometimes. And, the teacher was very willing to do it, and the school district didn’t let us do that. That would have been my only disappointment, because even into half way through the next year, Rachel’s coming home, ‘I see my teacher’--she’s referring to the first grade teacher. So there was a definite connection and I wish they’d been a little more sensitive to it. But, you know what, I understand how politics and whatever else, but it would have been very cool. I think at that point, that would have been my only real frustration. I’m just trying to think back. Otherwise, we continue to see her progress and

> her second grade teacher was really nice, so I have no complaints, but let's face it, who do we learn for? People we love and adore. So she did make, I think, more strides.

Mary and the other parents tried to lobby for the teacher to transition to the next grade level to continue the growth these students had experienced. The school district was not in agreement and blocked the proposal, leading to parents experiencing feelings of frustration.

Angela shared a trusting relationship with her son's ABA therapist and invited her to come into the school and train the staff on effective methods for working with Max. Angela explained,

> The principal was like yes, you get a one-on-one aid, yes, you get the teacher that you want, yes, Janelle can come in and work with your aides so that they're working with Max appropriately. So that year was unbelievable. It was very easy. We kind of went for it, everything was very good. Max's teacher that he got, all the other kids were assigned to her already, who was going to be in her class, so she had some challenging behavior kids in there on top of Max walking in. And Max wasn't, he's not, he wasn't aggressive or anything, but he's loud and he has a really hard time sitting through any type of lecture or talking. That kind of stuff. So, she got him on top of that and she did an amazing job. And she gave a shit, so that made a difference. And he was, Max was pliable. He's been in ABA for three years at this, three and a half years. He was incredibly used to being in like a therapy situation and having to sit down and work, so his, the having to kind of recircle and redirect him all the time was really minimal, because he was just so used to it. And they really worked with Janelle to kind of, when he was working on skills, whether it was counting or whatever, it was done kind of like an ABA way with appropriate reinforcement and that kind of stuff, so it just went really well. Honestly, I

> think the biggest deal was her coming in and working with the aides made a huge difference, because then Max wasn't distracting the entire classroom all the time with sounds or loudness, the occasional swearing--that definitely happened with Max, but because they could, like the aides could handle it, so it went really, really well. I had other families who knew Max and they're like we want who Max has because they knew that Janelle had worked with them.

Having the ability to hire an outside professional to train the staff was invaluable. The additional support and specialized training not only impacted Max, but other children in his class along with children in future grades. However, this benefit was short lived, as the principal the following year banned outside therapists from coming into the school.

Negative Relationships

Schools were also not in agreement to utilize outside supports funded by the parents. For example, Lisa hired Nicole's ABA therapist to come in and work with her teachers. While this lasted for a short period of time until the school prohibited outside support. Lisa said,

> They'd let Michaela [ABA therapist] in and she'd take notes and maybe offer something. And after a while like I said maybe half the school year they said no. There were a lot of factors, I think. That's when our psychologist came in. No that doesn't sound right. He came in first. This was in elementary school. Late elementary school. And yeah, we'd have a therapist go in. And even our lead therapist said you know that's unusual, schools don't usually do that. To let a therapist come in. But I have a feeling Nicole had gone through the injury and I think this was 'boss wants to make us happy'.

Although the district administrator briefly allowed the ABA therapist to provide service to Nicole, it appeared to be granted simply to make the family happy after Nicole had become seriously injured after a fall at the school, prompting legal counsel. However, this consolation was short lived. It’s unclear why these two district administrators did not allow outside professionals to support students when there was no financial implication to the district and these services provided academic and behavioral benefits to the students. Further, these outside services provided no-cost professional development to school personnel. This lack of partnership between the school district and mothers negatively impacted trust.

Relationships with Families of Children with Significant Disabilities

The importance of relationships carried over to other families of children with significant disabilities. When the mothers had the experience to interact with other mothers of children with significant disabilities, they felt a sense of community and connection. Mary liked the organized events facilitated by Rachel’s teacher, sharing,

> ...the teacher organized for parents to have social time together. Like once a month, a parent would take--each of us as parents took a month and we either have all the kids bowling, all the kids at our house, game night, whatever. It could be simple, come watch a movie at our house. It was like their social outing. It was very cool.

Mary felt a connection with the other parents who had children with significant disabilities. She also had an opportunity early on when Rachel started in elementary school to talk with other parents about programming for students in that school. Mary recalled,

> It was at a different school…. And we had meetings, actually because I was expressing concerns, they actually had another parent available to answer questions. So that was kind of nice. I had concerns--how do they get along with other kids? How closely are they monitored?

Mary was able to ask these questions and talk with a parent who had direct experience versus a teacher's perspective, which is generally different from the one of a parent of a child with a significant disability.

It can be isolating to be the mother of a child with a disability, often being excluded from social groups and mothers groups. Many mothers of non-disabled children meet each other and develop friendships through playdates. For a mother of a child with a significant disability, these play dates typically do not occur, leading to a lack of peer support. These organized events created opportunities for the parents of children with significant disabilities to socialize, develop relationships with one another and form a supportive network.

Christine found being with other parents in the waiting room at the clinic to be empowering, and provided an opportunity to be able to learn from others in similar situations, as well as teach new mothers how to navigate the system, leading to a path of advocacy and high expectations. She expressed,

> Supports and the education that we got from really early on being connected with families. Some of them had older kids and then as Hannah moved up, then there were younger families and they learned from all of us. We said 'Ope, nope! Sign language needs to be taught at one year' and we would kind of see how they were handling other people's kids and you just learn from each other and we empowered each other. It was really good and I think that's something that is really missing with birth to three now...the support to bring parents together is so important, because it gives you--it empowers you so much more than just being left on your own. I mean you can be told anything. And you probably know the research. Whatever you get, you're grateful for and you think it's really good when you have nothing to compare it to, you don't know. And I think that's

> why bringing parents together and I think a lot of the organizations like DSAW [Down Syndrome Association of Wisconsin], now has groups where they bring young families together. I'm sure the Autism Society tries to do that. I'm sure some of the disability related groups, but what was really nice was that we were all together with all disabilities, so I learned a lot about CP [cerebral palsy], I learned a lot about autism. You know? And, anyway, it was just, I thought one of the hardest things, but it was also the best thing. It was really difficult to live our life that way, running with two little kids all the time. It was, I have to say, it was really hard. That was the hardest part about having a child with a disability was that running, but it was worth every minute, because, I mean some of those families are still, they're still families I can call any time that you know you still have a connection. I mean, it's just--I think that that launched us into demanding better services and advocating and having much higher expectations for our child.

Christine was able to develop a network of supportive friends with whom she is still close. The development of this network was happenstance, as the parents were waiting for their children during therapies; this was not an organized event for these families. This waiting room time created fantastic learning and supportive opportunities to weave a network.

Relationships with Families of Non-Disabled Children

Alternatively, mothers were not able to build this same kind of trust in mothers of non-disabled peers through playdates or as the child got older, extracurricular activities. Being a parent of a child with a disability can be isolating, let alone having a child with a significant disability. Susan attempted to create friendships for her children and opportunities for peer role models, yet the parents of non-disabled children were apprehensive and did not understand the importance of developing friendships with a child who had a significant disability. Susan disclosed,

> So I remember meeting one parent um who had agreed to let her son [interact with Kate as a peer role model], but she wanted to meet me first. So I met her and she--her concerns had been that would Kate hurt her son. Would Kate--you know what I mean? And it was kind of like that and I just didn't feel good about that at all. I mean bravo to her that she was willing to consider it, but it was--I, you know--I pretty much pull back from anything that's, cuz it'll be difficult for me emotionally and to the detriment of my kids in some ways. My focus should have been on whatever it took, whatever sacrifice that I had to make should have been that I had regular kids coming into the home. Regular kids constantly, you know. I should have immersed them more in the regular kid opportunities. They just didn't really have the skills to fit in with that. And I remember I was shot down by a good friend of ours by the time, whose son had started spending time, I said would your son be able to come over and spend time with our middle son. And she said yes, and I was looking for it to be like an every week thing and of course he started coming and three weeks later, you know he couldn't because his mom signed him up for piano lessons. Well, I was devastated, because it was like that was my one access and like how could she have scheduled--doesn't she understand? And she didn't. You know. She didn't.

When a non-disabled child was not able to participate any longer, or the mother was concerned that her child would get hurt, it caused Susan to feel despondent and cease to promote these invitations out of self-preservation, further isolating her and her children instead of developing trusting relationships with peers.

Extracurricular Activities

Mothers of non-disabled children were not just apprehensive in the early years. In fact, the exclusion became more apparent as the children got older. Christine was surprised, hurt and angered by the exclusionary practices of her peers, mothers of non-disabled children. She remembered, “Um, hard. That was because people weren’t open minded about it. And I have to say our experience in [the school district], in high school for cheerleading and for drama, the parents were the biggest obstacles.” Christine had been involved with these mothers and their children since they were in kindergarten, yet the mothers were now unsupportive and had a closed-mindset about inclusive practices and legal rights for a child with a disability being included in extracurricular activities. While the students may have wanted to include Hannah, their parents felt differently, leading to Hannah being excluded from inclusive school activities.

Mothers of non-disabled children felt threatened that children with disabilities were earning positions on sports teams and roles in plays or musicals. These mothers felt the positions and roles should only be for non-disabled children who may need extracurricular activities to boost a college application. The reality is that no positions or roles were being filled by children with disabilities; there were often extra spots added to include these students. The mothers of children with disabilities had to strongly advocate by meeting with the teacher or coaches and administrators to urge the inclusion of their child in extracurricular activities. When the child was excluded, the mothers felt angry, hurt and excluded themselves. They felt disdain for the non-disabled children they had known for ten or more years, as well as for their mothers who were frequently the leaders of the exclusive practices. This negatively impacted the relationship that may have existed prior to high school. Christine recognized,

> The third year, again it was a smaller chorus, so much pressure from the parents because they were giving a slot that should go to some kid who would actually, it would help their college application, and they, they buckled to the pressure. They told Hannah if she wanted to be in the play she'd have to be in set. Stage Crew, which she didn't want to do. So that's, that was our biggest. Those were our biggest problems. The parents were terrible.

There was a misconception by parents of non-disabled students, that students with disabilities were taking spots away from their child. The parents of non-disabled students met with the teacher to express their frustration and disagreement with this inclusive practice and the teacher ended up excluding Hannah from being in the production, instead offering her a spot on the set design team. Hannah was excluded because of her disability.

Lisa also experienced exclusion during extracurricular activities. She recounted,

> I got an email one morning and it was addressed to all the swim parents and it was from another swim parent and it said just so you know, don't forget to pick up, I have a lot of stuff here from the sleepover last night and she listed everything and Nicole hadn't been invited and when I brought it to the attention, I was told her invitation got lost in the mail and I brought that up to the swim coach and he said, well do you want me to address that with the team? And I said no it's been addressed. I mean every single parent knew Nicole wasn't invited. So it was definitely addressed. They all knew. They all knew.

Nicole was never fully embraced by her swim team, only being fully accepted by the team manager. When Lisa found out Nicole was excluded from a team sleepover, she felt angry, sad and betrayed by the mother of the organizing team member. This exclusion and betrayal impacted Lisa's relationships with the other swim moms, leading to feeling insignificant.

The mothers fought these barriers by advocating for their children and facilitating their inclusion. As Christine explained,

> I felt that my role--I gave up working full time at that point. I gave up working and stayed home and my job was just run interference, to be ahead of her and to clear the path for her and to shelter her from the ugly, awful conversations that needed to be had, so that she wasn't walking into that. That I was two steps ahead of it to clear the way, so that her experience didn't have to be dealing with people's ignorance and limitations for her. And so that's been my life.

These mothers all made it their mission to clear the path for their children to have the best experiences, however they imagined those experiences to be, whether it was heavily focused on academics, inclusivity with non-disabled peers, or focused on safety and comfort.

Strategies for Navigating Trust: Relationships

Mothers learned that using relationships assisted in the negotiation for the needs of their child, such as an adaptive curriculum or inclusive programming. Two of the mothers established these relationships with staff through offering to volunteer in the classroom, sending personalized gifts and thank you cards. Susan disclosed,

> What also made it easy was, the school had started out seeing our family as a family and when I say family, that means me, someone to be defensive against. Someone who was expecting more than what she should be expecting. From elementary through middle school and high school became key people in those roles came to recognize that I was not to be feared. That I wanted to be part of a team. That I wanted to have input into what was going on with my daughter's education and the time she was there and was willing to do the kind things in return--the volunteering, the gifts, personal notes, those kind of

> things and what started happening was some of those things not the direct instruction, but some of the other things they started using... I think once you have one person on your side that one person can say ‘let me tell you about it from another perspective’, that kind of thing. But what happened is through the years, I became perceived as not someone to be feared.

Susan also had to earn the trust of the school district personnel and while it may have not been mutual trust, the district administrators came to see her as someone they needed to work with to provide the expected education for her daughter. The way Susan went about developing this working relationship was through acts of service (volunteering), gratitude (thank you notes) and gifts. Christine also found this strategy to work in her favor. She shared,

> I volunteered all the time. See my way of trying to get support from the teachers was trying to take things off of them if I could. So I would try to be Room Mom--ok you put extra effort into my kid, so I will do whatever I can do to support your class. I don’t want to be taking care of Hannah. I don’t want to be interfering with all of that, but if I can support your classroom in other ways, I want to do that. I always chaperoned. I was a Room Mom. I always did that. But I was not a helicopter mom with Hannah. I didn’t ride shot--and I always often was like they’ve just got to figure it out. They’ll figure it out. But when it went wrong we had to go in for that.

Christine was a presence in the classroom, offering to volunteer and chaperone on field trips. She took the pressure off of the teacher in hopes that the teacher would reciprocate by spending extra energy with Hannah. Christine described her presence as present, but not intrusive. She trusted the teachers to teach her child and manage any behaviors that arose.

Mothers used relationships to navigate their child’s special education. When one relationship changed or ended, a new relationship was established in order for the mother to ensure her child’s needs were being met. Mothers quickly learned how to build and use these relationships or to stay away from others to benefit themselves and their children.

Ecological Systems Theory and Trust

The ecological systems that were impacted with the theme of trust were the meso, exo and macro systems. Key strategies for navigation of their child’s special education in the area of trust that intersect with each system are listed in Table 1. Most of the strategies that mothers shared were at the Meso level, as mothers relied on their relationships and communication with school personnel to navigate their child’s education.

Table 1

Trust with Systems

Systems	**Key Strategies for Navigation**
Micro	
Meso	Communicating with staff Attempting to befriend mothers of non-disabled peers Developing relationships with mothers of children with disabilities Running interference against mothers of non-disabled peers Volunteering, gifts, thank you cards Building relationships with upper administration
Exo	Mother designing educational programming for her child.
Macro	Mothers educating themselves regarding legal rights and obligations.

Educational Stages and Trust

The theme of trust impacted five educational stages of the child's education, including birth-to-three, early childhood, elementary school, middle school, and high school. Key strategies for navigation of their child's special education in relation to the theme of trust as it intersects with each stage are listed in Table 2. Mothers created and implemented strategies for navigation at each stage. They attempted to develop clear and persistent lines of communication at almost every stage, while building trust.

Table 2

Trust with Educational stages

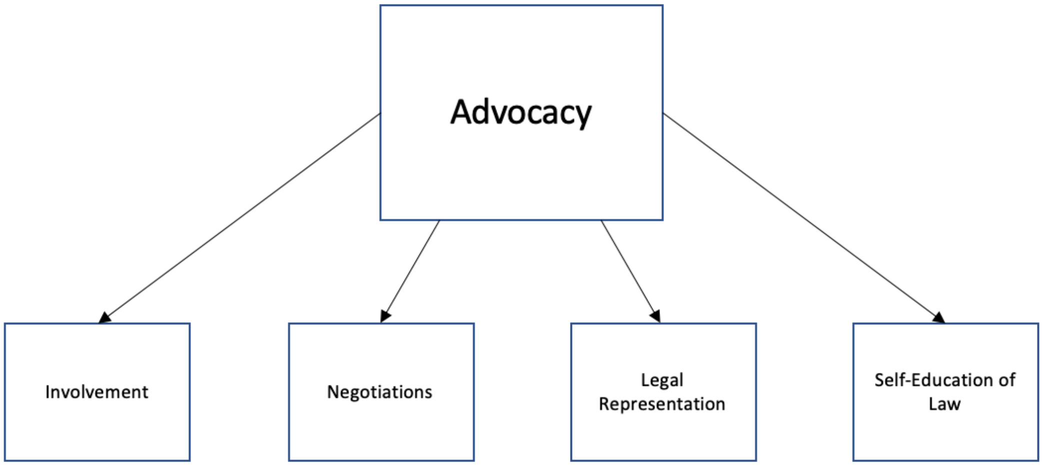
Stage	**Key Strategies for Navigation**
Birth-to-Three	• Developing relationships with mothers of children with disabilities
Early Childhood	• Communicating with teachers and upper administration
Elementary School	• Communicating with teachers and upper administration • Attempting to befriend mothers of non-disabled peers • Volunteering, gifts, thank you cards • Send child to a new school
Middle School	• Communicating with teachers and upper administration
High School	• Communicating with teachers and upper administration • Developing relationships with mothers of children with disabilities • Running interference against mothers of non-disabled peers
Transition Services	

Advocacy

The second theme of advocacy presented strongly in the findings, through mothers sharing their frustrations with the challenge of advocating for their child to be provided with opportunities to learn and participate in extracurricular activities. This included the seemingly constant negotiations and involvement that occurred for many of the mothers. Sub-themes of involvement, negotiation, legal representation, self-education of the law emerged as part of advocacy as seen in Figure 6.

FIGURE 6

Advocacy and Subthemes



Note. Concept map of advocacy theme and its subthemes. K. Wiseley, June 10, 2020.

Some mothers felt a sense of urgency and disagreed with predetermined programming, demonstrating their advocacy skills. Susan felt she did not have the luxury of waiting for her child's education and therapies. She knew what she wanted for Kate's programming and was going to advocate and negotiate for it. She remembered,

> This time it was like I don't have any time. Do not mess with me. This is the way that we need to do it. I hear what you're saying. I mean, I was very nice about it, I was certainly still not as confident as I became through the years, but I was, I knew that I was going to bank on ABA teaching and the way, and I was not going to bank on just general put her in a little class and have circle time. Because I knew that that was not going to help her.

> She was not going to get anything out of it and I wanted to take advantage of every opportunity I had for the people working with her.

Susan also did not care for the programming provided by the school, so she advocated for Kate's education by crafting by purchasing an outside curriculum and designing her programming. Susan said,

> Oh yeah, I bought it all. Again, some of it was, now there were some things that I knew I shouldn't have to pay for that I forced. I wasn't gonna force anything when it had to do with my child when she was in elementary school. I wouldn't have cared what I had to pay, because they were doing a good job for her. And they cared and they wanted to be a part of a team. So I was not going to go to them and say, oh and by the way now I want you to spend thousands of dollars. I mean, we found it on eBay or whatever. Now it was different elsewhere. But in that situation, I was not going to rock the boat and I didn't want to. You know? I didn't want to. I loved how that felt. It was, you know I felt like I could breathe.

Susan had to balance what she wanted for Kate's education, while understanding if she expected district administrators to fund her requests, it likely would not have happened due to budgetary constraints and would have caused a shift in her relationship with the team. Susan experienced tension because she felt connected with the team and wanted to positively impact her daughter, but maintain the relationship with the system.

Advocating for their children often caused challenges with relationships between mothers and school personnel. Kim shared how she gained confidence and began to advocate, leading to disagreements between stakeholders.

> I think eighth grade was when I really started figuring out I can't just go with the flow any more and it was freshman year we moved into that challenging situation with that teacher and so at that point I had really gotten my bearings. I'm trying to think, I was in my thirties, at that point I had had three kids. So I had learned a lot in life at that point and I wanted to take it and run with it and I'm her advocate and everybody else is going to do what they want and advocate for themselves in their own way. You know, 'this is my program, this is how I do things'. Well, no, this is my kid, this is what I want for her.

As Kim gained more experience with the school system, she gained confidence and began to advocate, leading to disagreements between her and school personnel. She wanted more individualized instruction than what was happening. Sadly, Kim never was able to get the programming she truly desired for Mariah.

Although all of the mothers advocated for their children's educations, at some points mothers retreated and were not as strong with their advocacy. Kim surmised, "I guess that's my own fault that I haven't spoke up. Um, I feel like it's also not my expertise, so maybe I am putting judgement out there where judgement doesn't need to be." Reflecting back on the start of her child's high school years, Kim was not happy with the related services and programming, yet she did not feel that she was an expert, and therefore did not address the issues at that time with the staff. This was a time when Kim chose to navigate by easing back. However, as the school year progressed, Kim became increasingly frustrated with the teacher and programming, leading her to strongly advocate for her daughter. She expressed,

> And so then I had a lot to say about that teacher and I made it very very clear and they ended up not keeping that teacher in the high school with her own classroom and moved

> her to the middle school. But I spoke up a lot and I was not happy. I had conversations with the principal.

Kim's strategy was to have frequent conversations with the principal. As she put it, "I was a thorn in her side. So then I actually saw action happen, which made me realize at this point that we always just need to be her advocate, because her communication hasn't really increased at that point." Kim found that the loudest complaints get the most attention.

Angela also found this strategy to work in her favor, creating action. Because of her advocacy, Max's programming was different from other students with significant disabilities. She shared,

> He wasn't shoved off in special ed like some of the other kids were, just because, you know what, it's the squeaky wheel thing. If you're like 'hey I want this done' and you're not on top of it or bitching about it 24/7, it's not going to happen.

Had Angela not been the "squeaky wheel", Max likely would be receiving an education that she considered subpar and segregated from his non-disabled peers.

Christine also stressed the importance of strongly advocating for your child, expressing,

> And what I've learned is you never hand over your dream to someone else. I am the keeper of the dream. Hannah, our family, Hannah is the keeper of her dream. We have people help us. I don't put the dream in somebody's lap and say make this happen. That's where a lot of people think, this is what I want, here do it. And that's the hard part about being a person, a family, a parent of a kid with disability is you are the keeper of that. You are the driver.

While some families follow the direction of the school, Christine found that she needed to be the one advocating and directing Hannah's education, otherwise it would not be what she desired.

For example, Christine wanted Hannah to have a life as much like her brother's as possible. She operated in the mindset of what society considers to be "normal" and its views on disability (Lalvani, 2013a).

Involvement

An unintended consequence of advocacy was mothers having to leave their jobs. Two of the mothers had to leave their careers to ensure that their children were receiving an appropriate education. They felt they needed to be at the school all the time because of the amount of advocacy they needed to do in order to ensure their child's needs were met. Angela expressed her frustration with the amount of time she had to spend at school advocating for and supporting her child, "I had to leave my job. My six-plus figure job. Because I was at school, like every other day. And my boss is like we have an open door--open campus policy, but this is getting out of hand." Christine also had to leave her career to care for her child and advocate for her child's education. It could be interpreted that due to staff's lack of knowledge and skills, training or investment, these mothers had to abandon their careers to provide the necessary supports and services their children needed at school. Although the mothers left their careers to support their children, the constant involvement and vigilance did not improve their children's educational outcomes, as they had hoped.

The mothers felt it necessary to stay vigilant regarding their child's education. Angela expressed,

> I just think like stay on top of everything all the time. Constantly look into stuff. Every option that you can, in everything. All the time. Never stop. It's exhausting. But if you don't, you're just going to get into this like latent, they're just not going to--I don't know how it is anywhere else, but I feel like because we were on top of stuff, people would

> always say to us, how did you get that? Because I made them do that. Because I was there. Because I showed up.

Christine felt similarly, stating "And yes, I always had to be completely engaged. Completely and fully engaged."

While all of the mothers felt they needed to be involved and engaged in their child's education, three of the mothers used the strategy of disengagement to protect their well-being during specific times in their children's educational journey. Christine recalled that,

> Middle school, I couldn't change it. It was like I couldn't change it. I mean we tried to impact what was happening in the classroom as much as we could, but I have to say, seventh and eighth grade--and the middle of seventh grade and eighth grade, I just totally disengaged. It was just like I just wanted the hell out of here, because it was like there was no way it was going to change. It just wasn't going to change.

As the school system was not going to change, Christine had to navigate the situation to protect her energy. She did this through disengagement with the advocacy process. Christine knew the way the school's policies and procedures regarding inclusion of students with disabilities would not change, though she tried hard to impact, and so, she had to be the one to change.

Susan also was tired of fighting with school personnel to make the changes she desired. As Kate progressed and she learned of new instructional methods, Susan had to evaluate her requests for changing Kate's programming, including adding new instructional methods and curriculum. During middle school, Susan did not have the energy to push for change and chose to disengage from this focus, referencing,

> I didn't have--I didn't have the skills and I didn't have the time and I didn't have the strength to say ok, keep my child in the regular ed, and now you're going to go in there

> and you’re going to develop a curriculum. We’re going to figure out what time of the day does she come in, when does she need to be pulled out. I didn’t have it in me anymore--even at that point--to force that. Nobody was doing that. That wording, there was none.

Lisa also experienced a stage of disengagement for protection. In this case, Nicole’s ABA therapist stepped in to facilitate communication from the school district during elementary school, as the negativity and fighting had gotten to be too much for Lisa to handle. She shared,

> And our therapist took very good care of us. It got to the point and I don’t know what year this was, but at one point, she--with permission--and she said to the school district, ‘You will put everything through me from now on and I will decide what Lisa needs to hear.’ And they did. They contacted her. There was about a year’s worth of that.

Lisa was able to use her resources and supports to help her through this time of disengagement by utilizing Nicole’s ABA therapist as a buffer. These mothers experienced tension between wanting to maintain vigilance and advocate for their children, while also realizing they were experiencing burn out and needed to practice self-care by disengaging from their advocacy for a period of time.

Mothers felt they had to be involved at all times, with differing degrees of intensity. Four of the mothers had to be strongly involved and advocate intensely during all of their child’s schooling. Two of the mothers did not feel they needed to advocate strongly until their children were in high school. The level of involvement and advocacy was exhausting, yet the mothers continued to press on for their children.

Negotiation

The process of negotiation is defined as two parties coming together to bargain for a mutual agreement. In this study, mothers negotiated with the system for the services and programs they felt were important for their children, such as increased related services (i.e. speech-language therapy), self-contained placement with adaptive curriculum, or specialized transition services. Susan's experience with negotiations began during birth-to-three services. Susan found she needed to advocate strongly for what she wanted, while also taking into consideration the offer that was presented. She explained,

> It did not go well. The speech pathologist bucked the system to the point that, yeah the services that we were being offered were not sufficient and they wouldn't agree to. I wanted more time with the speech pathologist for Kate, because that would be that one on one time and it was pretty much 'No' and so I filed a grievance. And I said it was based on your coming to me about my daughter with a pre-packaged plan that you feel might be relevant for other students and I'm telling you it's not relevant for Kate and your job and our job is to make sure we are addressing to Kate as her own individual needs and we have the research to back up what we are doing and if you have research to back up what you're doing, I'd like to see it. So they got a mediator involved. They got somebody right away from the head of the birth to three program who came out to our home and met with me and she was absolutely lovely. She was a great person and she said you know I hear what you're saying and she was very kind and didn't talk down to me and recognized what I was doing, agreed with what I was doing. And she said well how about we, I don't remember I think we ended up negotiating a little bit. And I was very happy with what we ended up with.

One of the strong strategies for negotiation noted by most of the mothers included using research and data to support their requests. Because Susan's husband was a lawyer and she was well-educated on the law, she used that knowledge to understand how to file a grievance. When she was met with resistance from district administrators, Susan would demand the administrators provide research to support their decisions, which never was provided. Susan, however, always presented research with any requests she made, strengthening her argument and ensuring those requests were met.

Lisa also used this powerful strategy of presenting research and data to support her request for the school district to pay for her daughter's specialized transition services program. Lisa recalled,

> She went through Project Search, so I told her we had gotten the letter and it's a $7,000 program, so we had gotten the letter that she was in and basically who is going to pay for it. And I went to [the district administrator] and I said, 'it's $7,000 a year' and they said 'ok.' And I said, 'well, you're paying for it'. And the director said 'why?' And I said, 'well you get $10,381 per child' and I said 'she's not going to be there at all, so you're actually making $3,000 on a kid that will never be there, so you'll pay or we're going to get a lawyer. We're going to play that game again. I don't care anymore.'

Lisa's negotiations were almost always contentious and involved threats of legal representation, which scared the district administrators. This strategy was successful for Lisa to secure her the funding her daughter was entitled to.

Susan understood that advocacy was really about learning how to effectively negotiate. For example, Susan's strategy for negotiation was three-part: considering the other party's stance; maintaining a positive and professional attitude, while also being assertive with her requests for her daughter's education; and protecting working relationships. She explained,

> I always had to weigh and balance 'How far do I go?' 'What do we get in return?' 'What happens if I do this?' It was always, it was incredibly difficult to navigate and try to

> maintain a positive, good relationship where, you know, I was seen as somebody who was still going to come in and be a part of what was going on…

Mothers felt the most confident in negotiating due to years of experience. In general, mothers expressed the importance of advocacy and involvement in their child's education, in order to support a stronger educational program. Mothers expressed their feelings that without advocacy, their children would have gotten a lesser quality education. For example, Angela stated,

> I just think like stay on top of everything all the time. Constantly look into stuff. Every option that you can, in everything. All the time. Never stop. It's exhausting. But if you don't, you're just going to get into this like latent, they're just not going to--I don't know how it is anywhere else, but I feel like because we were on top of stuff, people would always say to us, how did you get that? Because I made them do that. Because I was there. Because I showed up.

Christine felt similarly, stating,

> I think if you aren't engaged there's always and I don't want to call it a squeaky wheel thing, but if you're not clear about what your goals are, you get the standard just, it's the same with a regular ed kid, if you're not saying, if you're not on top of it, and you know, you know you don't get, people don't look at each kid and say we want you to--I mean we want you to get a decent education. You know, maybe not the best, maybe not the most personalized, and you'll do fine. And that's how it is with special ed, too. That's how it is.

Both Angela and Christine felt they had to be highly engaged and involved, always negotiating for a higher quality education at all educational stages. Had they not, they felt their children would have received an education that was full of low-expectations and quality. Mothers felt they had to be involved at all times, with differing degrees of intensity. Four of the mothers had to be strongly involved and advocate intensely during all of their child's schooling. Two of the mothers did not feel they needed to advocate strongly until their children were in high school. The level of involvement and advocacy was exhausting, yet the mothers continued to press on for their children.

Mothers used their knowledge and expertise, relationships with school personnel and outside professionals, and time to negotiate for their child's education. While not all negotiations were successful for the mothers, they gained experience in the art of negotiating.

Legal Representation

Two of the mothers needed to secure legal counsel as part of their advocacy efforts as a result of services identified in the IEP not being provided by the district. When Lisa became aware Nicole had not received months of speech-language therapy after asking her special education teacher why she had not received a progress report from the speech-language pathologist, Lisa recalled,

> when she wasn't given the minutes, we hired a lawyer, we sat with them, um, we told them we were prepared to sue, um, their lawyer...in a very pretty cashmere sweater and a skirt and pearls and stood there and said give them whatever they want, because we were right. My kid doesn't miss 660 minutes.

The special education teacher told Lisa the speech therapist was out long-term and there was not substitute therapist. Lisa was angry that Nicole had missed months of this important service that she was entitled to by law and Lisa was never notified by the school district. This was the final straw and Lisa brought in a lawyer, ready to sue the district. When the facts were exposed, it was clear the school district was non-compliant and the district's lawyer agreed to whatever Lisa wanted from throughout the rest of Nicole's educational career in an effort to avoid a lawsuit.

Susan also obtained outside legal counsel, suing the school district over an issue with her other child. The district did not want to enter into another legal battle and therefore, Susan's requests were often granted from that point forward. Susan realized the trauma this caused to working-relationships with the school system and therefore tempered her requests to the district, often purchasing her own curricula for Kate.

While the legal processes impacted working-relationships between the mothers and school personnel, this extreme measure worked in the favor of the mothers as their requests were often granted from that point forward, though not easily. Mothers still had to "fight" for what they wanted, yet they were able to get their child's educational needs met.

Self-Education of the Law

All of the mothers had to educate themselves on special education law in order to effectively advocate for their children's education. Without this knowledge, their children likely would not have received FAPE according to their IEPs. However, each mother was careful with how they presented that knowledge during meetings and other interactions with school personnel. Susan was well versed in special education law, having studied it for years after her older children experienced challenges ending in legal battles with the school district. Her strategy was to be knowledgeable, but not flaunt that knowledge. She explained,

> I wouldn't bring the law in, I wasn't that parent. I would just say 'it's my understanding that this is what's important to my child.' I kept coming back to make it about my child. I never brought in the legal stuff and highlighted it, and gave it to them--I never did that,

> but I used it you know. I don't ever ask for anything unless I've already done the research and I had the law to back it up.

Susan advocated for what she wanted for Kate's education using the law and research to support her requests. She was careful to remind the school personnel that her requests were to benefit Kate's education.

Although Lisa had to obtain legal counsel at least twice during Nicole's educational career, she still educated herself on special education law in order to get the services she wanted for Nicole. She remembered,

> I wanted like three-hundred, stupid, what like three-hundred minutes a week of something and it was the Director of Special Education who just kind of gave me that smirk and said well we can't do three-hundred minutes. And in my head I'm thinking I know that. I said, 'well, what can you give me, because according to', and then I could, see that's the other thing, you know, our therapists would give us stuff, so I could pound out IDEA, I could pound out No Child Left Behind. I knew that.

Without this knowledge, it was likely that the school would not have given her the services she sought. These services were not out of the ordinary; they were services that were in the IEP or were necessary for Nicole to meet educational goals and progress in her education. Lisa learned that she could ask for the draft IEP ahead of time so she could be prepared to address what was written, in addition to her own concerns and desires. She emphasized,

> It really wasn't until middle school that I would sit there with that IEP because I asked for the draft ahead of time. Got the draft ahead of time and I went with my highlighter [motions highlighting] and it wasn't until I sat down and I said I want to talk about this

> and this and this. And I also had read enough about IDEA and I had also read enough about ADA [Americans with Disabilities Act].

Being knowledgeable in the law gave Lisa credibility with her requests, since often parents do not have knowledge of the law. Mothers used the law, whether it was by educating themselves on the laws of disability and special education, or securing legal counsel when situations were dire and required increased support.

Strategies for Navigation: Advocacy

Mothers used multiple strategies to navigate their children's education through advocacy in order to get the education they expected. Strategies included, educating themselves on special education and disability law, negotiating services and programming, and developing relationships with school personnel and outside professionals. At times, mothers disengaged from advocacy as a strategy of self-preservation when it became too challenging or too much to shoulder. Mothers also developed relationships with other parents of children with disabilities to empower themselves to learn advocacy skills and in turn, teach new parents these skills. The navigation through advocacy was the hardest part for all of the mothers. It was stressful and often filled with angst and disappointment due to lack of collaboration, lack of effective instructional practices, and closed-mindsets leading to segregation and exclusion. However, all of the mothers soldiered on, to protect their children and attempt to ensure a successful outcome.

Ecological Systems Theory and Advocacy

The ecological systems that were impacted with the theme of advocacy were the micro, meso, exo and macro systems. Key strategies for navigation of their child's special education in the area of advocacy as it intersects with each system are listed in Table 3. Mothers demonstrated the most strategies at the Meso level, relying on relationships to support them and their attempts at advocacy.

Table 3

Advocacy with Systems

Systems	**Key Strategies for Navigation**
Micro	• Disengaging from process to promote self-preservation
Meso	• Advocating for extracurricular activities • Bringing in therapist to facilitate communication • Developing relationships with school personnel • Developing relationships with parents of children with disabilities to learn and teach how to advocate
Exo	• Involving self in all areas of child's education • Mother designed child's educational programming • Securing legal counsel
Macro	• Mothers educating themselves regarding legal rights and obligations

Educational Stages and Advocacy

The theme of advocacy impacted five educational stages of the child's education, including birth-to-three, early childhood, elementary school, middle school, and high school. Key strategies for navigation of their child's special education in relation to advocacy within each stage are listed in Table 4. Mothers demonstrated advocacy at every stage, increasing intensity as the stage progressed into middle and high school. The importance of understanding and referencing special education law was a strong finding. All mothers found this to be beneficial.

Table 4

Advocacy with Educational Stages

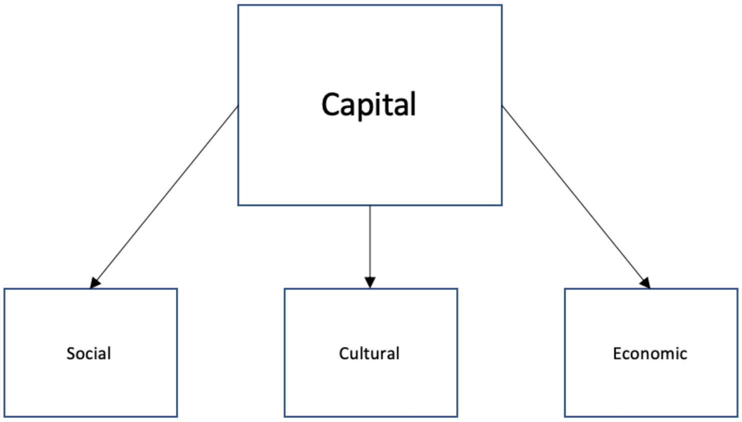
Stage	**Key Strategies for Navigation**
Birth-to-Three	• Developing relationships with mothers of children with disabilities
Early Childhood	• Communicating with teachers and upper administration
Elementary School	• Purchasing own curriculum and designing programming
Middle School	• Weighing and balancing negotiations--how far does one push to get something in return? • Mothers educating themselves regarding legal rights and obligations
High School	• Referencing special education law
Transition Services	

Capital

Capital is defined as wealth and status in society, whether it be financial, cultural or social. Bourdieu (1974) identified three types of capital: social, cultural and economic as depicted in Figure 7. Social capital is one's networks and relationships. Cultural capital is one's learned behavior, knowledge and skills. Economic capital is one's financial resources.

FIGURE 7

Theme of Capital



Note. Concept map of theme of capital and its subthemes. K. Wiseley, June 10, 2020.

All the mothers in this study had capital, including cultural capital: they were all white, educated, and middle to upper class. They also had social capital: being connected in the community with knowledgeable professionals in the area of special education and other families with children with disabilities, and economic and social capitals. Four of the mothers in this study had economic capital, which offered them the funds to access outside therapies and hire support staff and/or legal representation. Having capital is evidenced to even the power differential in parent-school partnerships (Trainor, 2010; Ruppar et al., 2017); however, even though all of the mothers had capital, they did not experience this evening of the power-differential and were still challenged to navigate the special education system, including finding sustained partnerships with school personnel.

Even though all of the mothers had cultural and social capital, each experienced challenges negotiating with their respective school systems. Most of the mothers' negotiations started out positive and then transitioned into a fight with school personnel very soon after starting public education. All of the mothers felt they had to fight for their child to have appropriate access to OTL at some stage in their child's K-12 education, regardless of their capital.

Social

For the purpose of this study, social capital is defined as being connected in the community with knowledgeable professionals in the area of special education and other families with children with disabilities. All of the mothers had social capital, although some mothers demonstrated their capital later than others.

Lisa's social capital offered her access to legal counsel, which empowered her to demand better services and hold the school district accountable for her child's education. She recounted,

> ...a very good friend of ours was Judge Martin Thomas. So we got on the phone and called the judge and this is when we started getting very empowered. And he said I've got a name of an attorney, so we had that in the wings.

Lisa's social capital also allowed her frequent contact with upper administration and created a direct line of communication. She told,

> And then, when they finally did let the speech teacher go cuz he had been sick so often, that night I got a phone call from the Director of Special Ed. 'Lisa, we're letting you know we're letting the speech teacher go we've hired a new speech teacher' and I said are you making this phone call 52 times and he said no. He said 'I'm making it to you'. Right. So you have a whole bunch of parents, God knows if their kids ever got it, ever got that speech and that's what I think is just, you know that's part of the reason, one of the reasons I agreed to talk to you, was because we're the lucky ones and our story is still messy, so what about all of those who have a messier story and it just stays messy?

The fact that the Director of Special Education only called Lisa to notify her of the change in staffing angered and frustrated Lisa, leading her to frequently wonder about the inequity of services for children whose parents did not or could not advocate strongly for whatever reason.

Susan's social capital offered her a relatively quick diagnosis of autism for Kate. She recalled,

> I started pretty early, well I took her when she was probably about a year… So nobody would believe me and I of course was excited thinking this is just me. But I knew that I'm not the kind of person to see things that aren't there. So I. Dr. Bill Jackson who is the head of Wisconsin Early Autism Project, which at the time was the only autism ABA provider. And so I had him come over...to see Kate. So he went into her bedroom, we went into her bedroom, and he sat down with her and she had her Legos out. And she um he asked if he could have a little bit of private time with her and I said sure and Kate loved to stack her Legos in the same order, red, blue, yellow, green. Red, blue, yellow, green. Of course nobody thought that was unusual, but me. And so I came back in about--he said 'give me five minutes', and I came back in about five minutes later and he said 'what can I do for you Susan? What can I do for you?' And I said 'well everybody's telling me that there is nothing wrong developmentally, so I'm asking you.' And he goes, 'oh yeah. Oh yeah she has autism.'

Due to Susan's network and relationships with outside professionals, she was able to have the head doctor come to her home and quickly diagnose her child, leading to starting early interventions with ABA therapies very soon after.

Angela's social capital also involved close-knit relationships with outside professionals, such as Max's ABA therapist, which led to her creating a team to fully support Max at a private school. She explained,

> Janelle was the person overseeing his whole special ed thing at this Catholic School in our town and then we hired three other aides for him that were one-on-one and what they were doing is we're kind of meshing ABA with his regular day and it was fucking awesome.

Private schools are not required by law to provide services and supports for children with disabilities, so Angela's social (and economic) capital offered Max to be fully supported and make progress towards his education.

Kim's social capital developed later in Mariah's schooling, when she became the District Parent Liaison after receiving training on IEPs, transition services, collaboration, communication and other special education topics. Kim's specialized training in this area supported and improved her advocacy efforts along with offering her connections with parents of children with disabilities.

Christine's social capital started her off on a path of having the best providers within days of her child being born and beginning Birth-to-Three services. She recalled, "Within ten days we were having some nursing issues and because my best friend was a birth to three provider in Westport County, she was able to get us with the best provider in the county." Christine's social network was able to allow her access to the best service providers from the start which set Hannah up for a path to success as well as Christine realizing how she expected to be treated by school personnel. Christine's social capital which allowed her to create connections with legislators, boards and committees and increased her ability to advocate for her child and other children. She explained,

> And I understand I'm in a special circumstance. I was able to do that and the beginning when we stayed home, my husband was starting his career. It was tough. It was tough. We were poor, we were broke. But you know, because I did it, he was able to concentrate on his career and it all worked out in the long run. I had to give up my career, which was really tough, but it has worked out. And this had kind of become my career, is disability advocacy. And I don't know, I just I just think so many--I think it's my role to do that because there's so many people out there that don't have what I have to do that. I sit on a lot of committees. I sit on boards at the state level. I advocate. I know so many state legislators.

Not only did Christine learn to use her social capital to advocate for systemic change at the state level, but with this knowledge, she strongly advocated for all students with disabilities to be educated in the general education classroom, thereby disbanding the segregated placements and fully-adaptive curricula for this population. This change happened after Hannah was done with high school, much to Christine's feelings of bittersweet; she had impacted the change, but it was too late for her child to fully experience this shift.

Interestingly, Christine's social capital and advocacy to impact changes to the programming and placement at Hannah's school, negatively impacted Mary's view of Rachel's needs being met. Hannah and Rachel went to the same high school, though Hannah was several years older than Rachel. Mary was not in agreement with the shift to fully included programming for all students with significant disabilities. Mary, and other parents, were not notified of this shift and strongly advocated against it once she became aware, using her social capital to obtain a connection as a key advocate with deep knowledge of IDEA. This connection was a special education teacher who was also an expert in the IEP process and helped Mary when programming changed without parent notification. She recounted,

> Um, and with the help of a friend who is a special ed teacher out of our district, she went through the IEP and she said because of some of the wording in the IEP, she goes, this is a restrictive environment. It's not a least restrictive environment. She goes, she should not be in this environment.

Mary had social capital, but did not use it to impact Rachel's education until Rachel was a junior in high school when she had her friend review Rachel's IEP, provide guidance and education on rights and procedures as it pertains to placement and LRE. This use of capital was effective, as the school district did reverse Rachel's placement decision and reschedule her in adaptive courses, which Mary felt were appropriate for Rachel's developmental level and educational needs. Mary's social capital offered her to strongly and confidently advocate for Rachel's placement when the school placed all students with disabilities in general education courses without parent consent and proper supports in place in order to meet the needs of each student.

Social capital offered the mothers a support system and pathways to getting their needs met. Without their social capital, their children would not have had the strong educational start they did, nor would the mothers have been able to advocate as well, as social capital is an important factor to effective advocacy (Trainor, 2010). Social capital (i.e. the relationships mothers had with school personnel, outside therapists, parents and other stakeholders) worked in the mothers' favor towards impacting change for their children's special education. However, social capital was not a fail-safe component to impacting immediate and lasting change. This was due to school culture not allowing true parent-school partnerships through breaking trusting relationships, as evidenced in the findings above, and possibly seeing the mothers as adversaries (Covert, 1995; Lalvani & Hale, 2015; National Council on Disabilities, 1989; Rehm et al., 2013; Stoner et al., 2005; Wang et al., 2004; Woods et al., 2018).

Cultural

In this study cultural capital is defined as being of the white race, middle or upper middle class, and having earned a college degree, along with knowledge of special education law, rights and responsibilities. All of the mothers had cultural capital and demonstrated this type of capital in different ways.

Christine increased her cultural capital throughout the years. She obtained her bachelor's degree and supported her husband to focus on building his career, leaving her job to care for her children. Although this was not her plan all along, she embraced her new position, learning all she could to impact systemic change. She said,

> And I understand I'm in a special circumstance. I was able to do that and the beginning when we stayed home, my husband was starting his career. It was tough. It was tough. We were poor, we were broke. But you know, because I did it, he was able to concentrate on his career and it all worked out in the long run. I had to give up my career, which was really tough, but it has worked out. And this had kind of become my career, is disability advocacy. And I don't know, I just I just think so many--I think it's my role to do that because there's so many people out there that don't have what I have to do that.

Christine's impact was strong, as she pushed for systemic change to the high school's inclusive programming, demanding self-contained classes be done away with and all students be educated in general education. She shared,

> I mean I'm sad that [Hannah] never got to experience it, but I'm happy that, I mean I was at school for some reason...I stopped in and there was like a--they have like a study hall where all kids go, but then that's where the kids with special ed might get extra help was during these study halls, but all the kids are in there, you know? And I was like wow, this is just amazing. I mean it just makes me cry, because that's what I wanted for Hannah. But at least it happened and hopefully--the Director of Special Ed and Student Services says it was parents like us that said, no this is what we want and it has changed.

Christine's cultural capital increased as she gained more experience and confidence with advocacy, blending her social capital with the cultural through networking and working to make systemic change at the high school, and now at the state level with different disability-related laws.

Lisa has a master's degree and has taken other graduate courses after her master's in the field of education. She feels her educational background helped her navigate her child's special education, though it was still extremely challenging and fraught with disappointment and upset. She lamented, "I thank God we have the educational background we do and the money we do." She often wondered about how other parents without the educational background and finances that she has could manage to fight for the services she negotiated for her child.

As she worked in the field of education, she had the summers off and was able to teach her child life skills to navigate middle school, such as how to work a combination lock on her locker. She recalled,

> I mean, middle school she got lockers and they wanted to put a key around her neck so she could open up her locker, well why don't you just put a big sign on her too? No, she'll learn her locker combination, but I need her in that building two weeks before

> school starts because she and I went every single day before school and practiced her locker. I'm home in the summer. What about parents who aren't? Their kids are walking around with a key.

Lisa was able to spend time teaching Nicole how to open her combination lock, while other children whose parents did not have this luxury, were subject to being singled out by wearing a key around their necks and not learning the skill. The practice left Lisa to pity these children and feel disgusted with the school for not teaching this skill leading to children looking different instead of fitting in with their non-disabled peers. Lisa's cultural capital helped her to support and educate her daughter outside of the willingness of the school system.

Susan's cultural capital was strong, as she was well educated, especially in special education law and student rights. She knew Kate would regress during the summer months away from school and wanted Extended School Year services. Each spring during Kate's early childhood and elementary school years, the IEP team would tell Susan that there were no services during the summer. As Susan was well-versed in the law, she replied,

> They even went so far as during the summer, because of course they would always say services are ended during the summer and I would say actually not. And so we would always have that conversation and we would always end up with Kate...receiving services throughout the summer, but it was not easy. Oh yes. And when I did, they said, 'oh no, you're talking about summer school. And here's how we do summer school and we do summer school at this school over here and it's a recreation program' and I said 'no no no, no no no.' See because by that time I had become educated in IEPs, I had become educated in law.

Susan advocated for Kate to maintain services during the summer using her cultural capital of education of the law. Susan also understood that using complex language of disability and professional jargon would achieve the IEP she desired. She learned that she could write Kate's IEP goals to be exactly how she wanted with no room for adjustment. Susan shared she,

> ...had orchestrated that IEP so tight that it completely and totally controlled everything they were going to do. This is the way--this is what we've been doing, this is what, I mean, so the IEP goals would say 'Using Distar Arithmetic two times daily, four times per week, Kate will…. Using Distrar, you know, learning at level B, subtopic C, Kate will'--I mean it was so tight there was no way that they would be able to break that IEP.

This strategy was very effective for Susan as it assured the curriculum and instruction Kate received was exactly as she wanted.

Angela used her knowledge of special education law to support Max's participation in cross country and track. Section 504 of the Rehabilitation Act (1973) states school districts must provide reasonable accommodations and modifications for students with disabilities in order to ensure an equal opportunity for participation in extracurricular activities. As such, Angela knew that Max would benefit from having someone run alongside him during practices and meets. She also knew the law required the school district to provide this service. She explained,

> Oh yeah. Like Max's guide runner, I mean technically, by law the school has to provide a guide runner for him, but I found a guy who lived across the street from the high school and was, he's an Iron Man finalist and was self-employed and was available at 2:30 every day and just loves high school cross county. It was super random; I found him the day before practice started his freshman year. So he, and we paid him out of the waiver for respite and it was awesome. He made more than the coach did for the season. So it

> worked out really well. And Max got a real trainer. And [the guide runner] just had like crazy expectations. He's like 'we're running, no walking. Go.' And it was phenomenal. I mean, Max dropped thirty five minutes off his--in two races because [the guide runner] wouldn't let him walk. I was like see, when you don't let him push you around he does amazing things.

Although the school district's responsibility was to provide the guide runner, Angela did not trust they would hire someone fully competent, so she sought out an adult who could fill this important role. She knew the expectations of the sport and what Max would need, along with interviewing people who were comfortable working with a child with autism in this capacity of training for cross country and track. Angela also used her knowledge of effective instructional practices and behavior modification to monitor her child's progress, or lack-there-of, along with her knowledge of IEPs to become the facilitator at IEP meetings. She explained,

> Well, it felt like I only had this option. You know, we financially couldn't fork out another sixty grand in one year. Um, and you know it was, so at that point I was like just give me the impression that you're going to work with me kind of a thing. Because I called them and it was, it was stressful because I didn't believe anything they said. We had when Max did his transitional kindergarten, he did it at [our home school district], and you know, there was no aide for him, even though it was in the IEP. There was all this stuff in there that they never worked on. So I dropped out of my master's program because I would stop in there and Max would just be dee-dee-dee hanging out in this--it just was so unsupervised. There was no working on anything going on whatsoever. So, I dropped out of my master's program for speech-path and I was like 'ok now I gotta come here all the time because you guys aren't doing any of this stuff.' So, kind of walk back

> in there, was ridiculously anxiety ridden. And because all of the other process with them was always so hard and always like banging heads. Just hoping that they say what they're going to do. You have to count on them and they don't--whether they have intent to want to do a great job, or not, they don't know what they're doing and they don't seek help. So, and they still don't. My kid's a senior and they still don't. So, we just did everything outside of school. I'm just like fine. I can't argue with you guys any more. He has had some phenomenal years, but his IEPs are like twenty minutes, thirty minutes long. I'm like let's just kick it out, what are you working on, let's go. And then give me a better progress report than one. Like I don't know if you've ever seen the progress reports? I'll forward you one. They're stupid. They literally don't say anything--working towards, ok we've been working towards that goal since second grade. At home he has been mastered that since second grade and you guys can't get him to do it there.

Angela's cultural capital shaped her view of the school district and teachers who worked with Max. She began to see them as not being competent to effectively teach her child, in addition to running an IEP meeting. Angela began to step into the role of facilitator to streamline the IEP meeting, while also not putting much trust in the process and purpose of the IEP.

Kim used her cultural capital to educate parents of children with disabilities on the nuances of related services (i.e. OT, PT, speech/language therapy) in the IEP. She shared,

> Yeah, I think what surprised me was when she started to phase out of therapies so she phased out of OT and there were still things she couldn't do and I was told that we can't help you with those things, so for example she wasn't strong enough to get her seatbelt off, but because the seat belt has to do with life outside of school, they wouldn't help with that. And so, but she could do buttons and she could do zippers and those things, so

> they graduated her out of OT. And it just really surprised me that they weren't able to assist with those types of things and it wasn't until we got into middle school she had the strength through practice of being able to do those types of things. And then she eventually got out of PT, too, um, but I felt like there was still room for her to be learning and expanding and growing. And the one piece of advice I give people all the time is once you have a service removed from your IEP, good luck. Like do everything you can to hang onto it, even if it's just for ten minutes because then if you ever need to increase it, it's way easier because it's still here. I feel like once those services are gone, they're gone. Because I know we had talked about bringing stuff back for physical therapy and occupational therapy, and it's nearly impossible, so I think that was the--I was excited, shocked. Yeah. Yeah. That she was being removed from those therapies, so by the time she got into middle school she was only speech therapy. Is all that she had.

In Kim's role as District Parent Liaison, she educated parents of children with disabilities on how to advocate and what to be aware of in IEPs, including service entitlements. Due to mistakes she felt she made because she was not aware or did not have enough education regarding it, she learned what parents should take notice of and assert their child's need, such as maintaining OT services or consultation.

Mary may have been able to better advocate for Rachel and other students with significant disabilities if she had more cultural capital. She recalled, "So that was a debacle year. It really was. And I know other parents really struggled with it, too. It's kind of like you felt like, well wait a second, what are our rights in all of this?" Mary did not have the knowledge of special education rights and responsibilities that all of the other mothers did. It was not until

Rachel was a junior in high school that Mary felt the need to research special education law, as she was mostly content with the services Rachel received up until that point.

The mothers varied with their level of cultural capital, with some beginning their child's educational career with high levels and others not developing it until near the end. Even with this variation, the mothers all used their cultural capital in an effort to produce positive outcomes for their children, though not all were entirely successful. Cultural capital did not improve the trust between mothers and school systems, and therefore could not be considered a successful component towards ensuring positive outcomes; although the literature shows capital offers a power balance and greater ability to advocate for positive outcomes (Bourdieu, 1986; Lake & Billingsley, 2000).

Economic

In this study, economic capital is defined as having financial wealth, which offered the mothers the funds to access outside therapies, hire support staff and/or legal representation, or not have a full-time job outside the home, which allowed them the time to advocate and be highly involved in their child's school. Not all of the mothers had economic capital to benefit their children's education.

Christine's economic capital was used indirectly to benefit her child and others. Christine's husband was a successful businessman, whose income allowed Christine to stay home to care for their children and become a strong advocate for Hannah's education. This situation offered Christine the opportunity to become an advocate for systemic change at the state legislative level. She shared,

> ...having a child with a disability is so much work to have them live a good life is so much work, but boy, high expectations and having the ability to clear the path. And I

> understand I’m in a special circumstance. I was able to do that and the beginning when we stayed home, my husband was starting his career. It was tough. It was tough. We were poor, we were broke. But you know, because I did it, he was able to concentrate on his career and it all worked out in the long run. I had to give up my career, which was really tough, but it has worked out. And this had kind of become my career, is disability advocacy. And I don’t know, I just I just think so many--I think it’s my role to do that because there’s so many people out there that don’t have what I have to do that. I sit on a lot of committees. I sit on boards at the state level. I advocate. I know so many state legislators. One of the reasons I was late, is I was sending emails to legislators about some laws, some bills that are going through right now. And working on that to make sure that they cosponsor and know what’s going on and explain it to them.

Christine’s economic capital has benefitted Hannah and other children and people with disabilities through the time Christine has put into advocating at the governmental level to change policies and laws. Had she maintained her career, it’s unclear if the strong advocacy would have occurred due to a lack of time.

Lisa’s economic capital was mainly used for legal fees, although she was financially secure enough to stay home in the summer with her children and not work a second job, as some teachers do to supplement their incomes. She asserted,

> So, but here’s the thing...my husband and I have money. You wanna play the game of suing us? Guess, what? I can play it back. Not that I have unlimited funds, but I’ll put the fear of God into you. And that’s why when it came time, like I said for the speech, and we were walking out with our attorney, I said we’re one of 53 kids on his caseload. I said when do we go class action? And he said, you don’t. You have to work for your daughter.

> And I said what about the other 52? Can't do it. Can't do it. That's where the travesty was.

While Lisa had the economic capital to hire legal counsel and proceed with a lawsuit if necessary, she lamented for the families who did not and were not getting the services their children were entitled to by law, yet the school district was only contacting Lisa due to her threat of legal action.

Susan's economic capital was used for therapies, hiring outside professionals, including legal counsel, attending conferences and purchasing curriculum. As Susan had a high level of economic capital, she was used to using this to her benefit through hiring people to help her in various areas of her life. For example, Susan referred to using her financial resources to hire legal counsel to stop a placement change for Kate during the last year of Kate's early childhood programming. Susan was invited to a meeting, which she thought was just a simple meeting regarding Kate's IEP, yet it was actually a meeting to plan for Kate to move to a different school. Susan expressed,

> I was furious that I was caught off guard. Furious at myself that I had not recognized what was going to be happening at that meeting, you know, because then I could have gone in, you know, to be better prepared. Or I could have used my resources outside to stop it.

Susan liked to always be prepared, including educating herself and having supportive people to advocate alongside her. What she thought was a simple meeting, turned out to be a transition meeting, of which she was not prepared. She wished she would have known, so she could have used her capital to prepare and be ready to stand her ground at the meeting, even hiring a lawyer to support her stance. Alas, she was not prepared, leading to the school making a decision regarding her daughter's placement without her agreement.

Angela's economic capital was used to pay for support staff, private therapies and to train her child's school personnel. She explained,

> The only reason Max is, is because I'm like he wants to go to that, so and I'm always like I'll pay for the aide. Every year for Homecoming I pay this guy who's an aide. I give him fifty bucks so that he can hover around Max to make sure nothing happens.

Though the school district should provide a paraprofessional to support children with disabilities attending extracurricular events, Angela did not feel that the paras provided were sufficient and made her child appear more out of place, so she paid out of pocket for a para she feels is an appropriate match for her son helping him participate, but remain unobtrusive and will text her photos during the event.

Angela has the means to pay Max's staff to attend specialized training in order to better meet his needs and effectively educate him. However, the staff does not take her up on this offer, frustrating her due to lack of effective teaching, along with hearing staff complaints of lack of time for professional development. Angela explained,

> There's nothing more frustrating than listening to special ed teachers bitch that they don't have enough staff, but in the summer they won't take extra--I offered to pay teachers and aides to come work with KLAS while they go work with Max in the summer. They're like, no that's our time. You've already said that you don't know what you're doing. I'm going to pay you to actually learn how to do this. So, that just tells me that you don't give a shit. And that's any field. I don't care what you're in. If you're not willing to learn extra

> on your time off, then what the hell are you doing? You're not going to do that on your regular day. So there hasn't been a lot of motivation that way from staff.

If the school is not providing the necessary professional development, it falls on the parents to provide this for their children, most often at a high cost and not always approved by the school district.

Mary had economic capital as defined by owning a home and being a stay-at-home mother, however, she did not have the level of economic capital the other four mothers had. While Mary had homeschooled her older children, she did not have the option to do that with her daughter, as Rachel required related services that were too expensive for Mary's family to afford out of pocket. She shared,

> If she stayed home we wouldn't have been able to afford the services. Because there's no help for them at that point. In order for us to have PT, OT, the things that had helped her so much, she had to go to early childhood or it was out of pocket. Those were the choices, so that's what we went with.

Mary had to send Rachel to public school in order to get her the services she needed, as the cost of private therapies would have been more than what Mary's family could afford.

Kim and her husband did not did not have the funds to afford a home in an affluent school district and also did not consider the school district's offerings and amenities when they needed to move closer to their jobs. Kim quickly found out the school district was not able to offer the services she expected and needed. She had to find alternate transportation, as she did not have the economic capital to offer her the luxury of staying home and transporting her child to school. Kim shared,

> So we chose that house because it was close to work and that was the school district that we were in, but that, too, I was so uneducated on questions to ask. I just assumed that there would be bussing, because I grew up in the country and every school had bussing. This district doesn't have bussing. So it created challenges for us when she was doing half days and even full days. Like we ended up putting her into childcare and I was just very thankful that her childcare had bussing for us because I don't know how I would have had a job and gotten her to and from where she needed to be.

Although Kim has gained economic capital over the years, she has not needed to use her economic capital to advocate for Mariah's education. She has used her social and cultural capital instead.

Mary and Kim did not have extensive economic capital to use in order to benefit their child's education, including providing for outside therapies or transportation, and therefore were dependent on the school system to provide all services for their children's education. Lisa, Susan and Angela were able to use their economic capital to supplement their children's education and did not have to fully depend on the school district to provide all of the education. Two of the mothers had to seek legal counsel as their children were not receiving services in which they were entitled.

Ecological Systems Theory and Capital

The ecological systems that were impacted with the theme of capital were the meso, exo and macro systems. Key strategies for navigation of their child's special education in the area of capital as it intersects with each system are listed in Table 5. Mothers demonstrated the most strategies at the Exo level, relying on their connections with government officials and attorneys to impact change, whether it was legislatively or direct impact for their child in the school.

Table 5

Capital with Systems

Systems	**Key Strategies for Navigation**
Micro	
Meso	• Interacting with upper administration
Exo	• Developing connecting with legislators to impact change • Developing connections with legal counsel • Working in field of education which allowed summers off to support child
Macro	• Referencing law during meetings

Educational Stages and Capital

The influence of various kinds of capital that were available and advantageous to mothers and their families impacted the five educational stages of the child's education, including birth-to-three, early childhood, elementary school, middle school, and high school. Key strategies for navigation of their child's special education in relation to capital as it intersects with each stage are listed in Table 6. As early as the stage of elementary school, mothers began to increase their use strategies to navigate their child's education. As the educational stages increased, the strategies expanded to include the services and supports of outside professionals. This was necessary as most of the mothers did not have enough power or influence on their own to impact the changes and programming they desired.

Table 6

Capital with Educational Stages

Stage	**Key Strategies for Navigation**
Birth-to-Three	• Developing connections in disability community • Resigning from career to support child
Early Childhood	• Mothers educating themselves regarding legal rights and obligations
Elementary School	• Bringing in therapists to train staff • Developing connections with legal counsel • Developing relationships with upper administration • Designing programming • Paying for private school and staff • Mothers educating themselves regarding legal rights and obligations
Middle School	• Developing connections with legal counsel • Developing relationships with upper administration • Teaching own child the skills necessary for secondary education during the summer break • Paying for private therapy and tutoring • Purchasing curriculum and designing programming
High School	• Bringing in advocate to review IEP • Mothers educating themselves regarding legal rights and obligations • Purchasing curriculum and designing programming

	• Paying for support after hours for extracurricular activities • Resigning from career to support child in school
Transition Services	

Most importantly, all of the mothers in this study had capital and chose to use their capital in different ways in an effort to ensure positive outcomes for their children. No one type of capital was solely used by any of the mothers. All of the mothers used a blend of capital types to benefit their child's education. Despite all of the mothers having strong social and cultural capital, and most of the mothers having strong economic capital, each still experienced immense challenges navigating their child's special education. Mothers were missing collaboration, trust, communication, and being viewed as the experts on their own children. Mothers were considered "outsiders", even with their capital. Mothers attempted to use their capital to navigate special education services during all educational stages. Regardless of their capital, there was never a true and sustained partnership between the mother and the school system. In essence, capital did not seem to matter. While parental participation is a mandate under IDEA, none of the mothers felt connected or that their input mattered and truly made a difference for their child during their educational career. It would seem that while parental participation is mandated, school personnel may have a difficult time finding ways to ensure parents are fully engaged members of the team.

Summary of the Findings

The three themes identified in this study were trust, advocacy and capital. Mothers wanted to trust the school, including its programming and personnel, but were frequently met with barriers that undermined their trust. Strategies for trust included, communicating with school personnel; investing time and money through volunteering, gifts and thank you cards to teachers; developing relationships with parents of children with disabilities; attempting to develop relationships with mothers of non-disabled peers and contrary to those attempts, running interference against mothers of non-disabled peers; choosing the school child attended; and educating themselves regarding effective practices, legal rights and responsibilities.

Due to a lack of trust, mothers had to learn to advocate for their child's education, gaining knowledge and confidence with this skill of advocacy as they experienced their child's education. Advocacy strategies included developing relationships with school personnel, outside professionals and parents of children with disabilities; educating themselves on effective instructional practices and programming, along with special education and disability laws, rights and responsibilities, including securing legal counsel when necessary; engaging in frequent communication with school personnel and becoming involved in all areas of their children's education; and practicing self-perseveration through disengagement when the stress became overwhelming.

Although the literature asserts that capital is an asset that can help equalize the power differential in parent-school partnerships (Trainor, 2010; Ruppar et al., 2017), none of these mothers found that to be true. There was always a power struggle and differential between the mother and the school system, whether it was the mother having greater power due to the backing of legal counsel and lawsuits, or purchasing their own curriculum and designing programming, to the mother disengaging due to having seemingly no power to impact change. Strategies related to mothers' capital included, developing relationships with upper administration and stakeholders in the disability community; making connections with legislators to impact systemic change; resigning from career to support child in school; developing connections with legal counsel and utilizing their services; financing private therapies, private school, tutoring and support staff for extracurricular activities, along with professional development for school personnel; teaching own child the skills necessary for secondary education during summer break; purchasing curriculum and designing programming; choosing the school child attended; and educating themselves regarding effective practices, legal rights and responsibilities and referencing law during IEP meetings.

Navigation of special education would have been easier for the mothers if the schools would have been open-minded and partnered from the beginning, as is designated in IDEA. All of the mothers experienced a "fight" during their child's schooling, whether it was at every stage or just the final stage of high school, despite their capital.

The theoretical frameworks used to support the data analysis were integral to the understanding of mothers' strategies for navigation. Ecological Systems Theory supported the finding of the mesosystem (i.e. mothers' relationships with school personnel) experiencing the most intersection with mothers' strategies, as relationships were the cornerstone of navigation. Educational Stages showed that as the stages progressed, the mothers' strategies for navigation became more intense and frequent. During each stage, mothers found communication with teachers and administrators to be paramount for how they navigated their child's special education. In summary, mothers used relationships, knowledge and capital to navigate their child's education. The navigation was never easy and most often unpleasant, but they persevered in the name of a mother's love and dedication.

Chapter 5

Discussion

The purpose of this study was to understand the experiences of how mothers of children with significant disabilities navigate the education of their children from diagnosis through age 21. I used a retrospective phenomenological approach to the qualitative study. The importance of the study was to make a significant contribution to understanding how mothers see the process and how school systems might facilitate bringing mothers in as meaningful partners so that the partnership can improve the quality of educational outcomes for children with significant disabilities.

The participants of this study were six mothers of young adults with significant disabilities from metro Milwaukee. All mothers identified as white, college educated and middle and upper middle class.

Review of the Findings

The findings suggest that mothers were challenged to develop and sustain partnerships with school personnel due to issues with trust. In addition, mothers did not trust the implementation of their children's programming. The mothers felt it necessary to be fully involved at all of their child's educational stages. Even with all of the mothers having social, cultural and economic capital, they struggled to advocate effectively. All of the mothers felt the need to advocate for their child's educational programming at some point. Most of the mothers' negotiations started out positive and then transitioned into a fight with school personnel, some soon after starting public education. All of the mothers felt they had to fight for their child to have appropriate access to OTL at some stage in their child's K-12 education. For most of the mothers this happened at every stage; for one mother this fight was not experienced until late in high school.

The findings will be detailed in the following sections. First, I will compare the findings to the literature as it relates to each theme: 1) trust, 2) advocacy, and 3) capital. Then, the conflicts with the literature will be presented. Next, the importance to the field, implications for practice. Finally, future research and the study's limitations will be discussed.

Trust

Mothers wanted to trust their children's teachers, therapists and other staff, along with the implementation of their special education programming. This was challenging as there were many barriers to maintaining and deepening the mothers' trust, which will be explained in detail below. Strategies for trust included, communicating with school personnel; investing time and money through volunteering, gifts and thank you cards to teachers; developing relationships with other parents of children with disabilities; attempting to develop relationships with mothers of non-disabled peers and contrary to those attempts, running interference against mothers of non-disabled peers; choosing the school child attended; and educating themselves regarding effective practices, legal rights and responsibilities.

School Personnel

Mothers demonstrated implicit trust with school personnel as supported by Angell, Stoner, & Shelden (2009), when they began their child's school experience and took for granted a sense of hope in the system, believing that school personnel were experts, had all the answers and would do the best for their child. While this was short lived for most of the mothers, Mary had this implicit trust for most of Rachel's educational stages.

When school personnel engaged in frequent communication and demonstrated knowledge about a child’s disability, as Lisa, Mary and Kim experienced with their children’s teachers, trust was increased, as supported by Angell et al. (2009). Strong communication facilitated favorable and constructive working relationships between mothers and teachers, such as Susan, Mary and Kim experienced during their children’s middle school years (Lake & Billingsley, 2000). At some point during their child’s education, all mothers had an experience of trust that was facilitated by good communication with school personnel.

Mistrust

While all of the mothers experienced points where they trusted, mistrust developed based on a pervasive belief that that general education teachers were not prepared or were unwilling to teach children with significant disabilities. This supports the findings by several studies which show mothers’ fear of the abilities of general education teachers to provide quality instruction to their children (Leyser & Kirk, 2004; Palmer et al., 2001; Ryndak et al., 2008). Furthermore, mothers’ perception of a teacher’s competence impacted their trust in the relationship, supporting aligning findings by Angell et al., (2009).

As several of the mothers’ children rarely met their IEP goals, mothers began to mistrust the implementation of their children’s IEPs which supports findings by Shelden et al. (2010) about how mothers had to increase monitoring of the child’s educational programming leading to a loss of trust. In addition, mothers felt the school administrator could increase or decrease trust. Interactions with school administrators were either favorable towards mothers’ requests being granted or aversive interactions leading to mistrust.

Equal and accepted participation in extracurricular activities was a challenge for half of the mothers in this study. They experienced push-back from non-disabled peers, mothers of non-disabled peers and teachers who coached the teams or supervised the clubs. The lack of teacher support aligned with research showing barriers to access and participation from staff not having the training and skills necessary to support students with significant disabilities, to low-expectations of successful student participation, along with not wanting to take the lead role in facilitating participation and supporting these students (Carter et al., 2010; Pence & Dymond, 2016).

Susan, Lisa, and Angela are all mothers of children with autism. They each had to engage in intensive negotiations to influence the services their children received which contributed to their low trust of all teachers and administrators. This is in keeping with research by Stoner and Angell (2006) who found that mothers of children with autism who had to intensify their negotiations for their child's access and monitoring of their child's education had low trust with school personnel. Literature showed that a mother's disposition of trust with other relationships in her life impacted her ability to trust school personnel (Angell et al., 2009). I did not seek to determine how trusting mothers tended to be in other areas of their lives, though this would have been an interesting component to my study and perhaps offered an explanation for the challenges with trust mothers experienced.

Implementation of Programming and Placements

Half of mothers experienced tension between what they wanted for their child's access and what they believed to be the implementation of the general education curriculum to students with significant disabilities. They believed the curriculum was too challenging even with accommodations or modifications. The other half of mothers never wanted full access and instead preferred self-contained and adaptive programming during all educational stages. These mothers had children with some of the most involved needs, echoing the findings of Palmer et al.

(1998) which showed that parents that are against full-inclusion typically have children with the most significant special needs, questioning the benefit of the inclusive environment. One school shifted its programming from self-contained to inclusive without the consent or input of the parents. One mother feared the decision to put the students with significant disabilities in general education was to maintain compliance with the state. These descriptors align with research by Palmer and colleagues (2001) which found parents against inclusion may feel that the inclusion movement happened without their input and consent and could view it as a “social or educational experimentation with their child’s well-being at stake” (p. 481).

Mary feared Rachel would be unwelcome and unaccommodated in general education as found in a prior study by Palmer et al. (2001). She described the self-contained classroom as a safe haven for the students, directly supporting the literature which found parents who were fearful of their child being socially isolated or rejected by general education peers, along with being uncertain of the qualifications of general education teachers to teach their children, tended to feel that self-contained environments were a “safe haven” where children with significant disabilities were always welcome and accepted and had teachers who were specifically trained to teach them and meet their needs (Connor & Ferri, 2007; Lalvani, 2013a).

Relationships with School Personnel and Professionals

Mothers used the strategy of developing relationships with school personnel and other professionals to their advantage in advocating for their children’s education. When relationships were positive and supportive, it was found that mothers’ feelings of trust increased, along with valuing the school personnel’s knowledge and training, supported by a study by Elbaum et al. (2016) which found when schools prioritized communication with parents, relationships improved. Half of the mothers had strong relationships with outside professionals and used this to supplement their child's education, aligning with research by Lake and Billingsley (2000) showing parents who have capital will seek outside resources to educate their children and not depend fully on public school options to meet their child's needs. These outside professionals were not fully welcomed by the school system and only allowed briefly to support the children in school, creating negative relationships between the mothers and the schools.

Relationships with Parents

Establishing relationships with parents of children with disabilities and creating a supportive network was another strategy used. These mothers were able to share ideas, learn and teach how to advocate and feel a sense of community with one another. These findings align with those by McConnell, Savage, & Breitkreuz (2014), which found parents who had strong social supports experienced less stress and even with increased stress, experienced greater positive outcomes due to their social supports. However, mothers were challenged to establish relationships with parents of non-disabled peers in an effort to support their child's access to inclusive activities such as play dates and extracurricular activities at school.

Advocacy

Advocacy was an area of frustration for all of the mothers. Constant involvement and negotiations did not lead to successful outcomes the majority of the time, unless legal counsel was brought in, perpetuating the frustration. Mothers gained experience and confidence and realized the importance of educating themselves on the law in order to increase their effectiveness with advocating. Mothers discovered it was up to them to advocate for their children's education; no one else was going to do it.

Studies have found different types of advocacy styles used by parents of children with disabilities (Rehm et al., 2013; Trainor, 2010). The mothers in my study all used several types.

Susan used three types of advocacy styles: disability expert; strategist--with her in-depth technical knowledge, references to and focus legal documents, and measured communication style; and high profile--being highly involved and demanding the best services, even leading her to design Kate's programming herself and purchase curriculum.

Christine used two types of advocacy styles: strategist--with her in-depth knowledge of policies, procedures and rights, and measured communication style; and change agent--teaching new parents of children with disabilities how to advocate and what to look out for, along with to this day working with legislators to implement laws positively impacting people with disabilities.

Angela used two types of advocacy styles: disability expert and high profile--being highly involved and demanding the best services. She also fought for her son's services and education, which is another characteristic of a high-profile style.

Mary used two types of advocacy styles: the intuitive type of advocacy only after she encountered adversity with the high school from program changes and lack of being informed. The second style was grateful-gratifier. She viewed her relationships with school personnel as trustworthy, respectful, and satisfying. She viewed Rachel's disability similar to school personnel, describing the view as "realistic".

Kim used two types of advocacy: intuitive--knowing what was best for her child and informing school personnel, though they did not always take her input into account. Strategist was the second style, happening beginning in middle school and increasing as Mariah advanced into high school. As Kim was trained as a parent liaison, she gained in-depth knowledge of policies, procedures and rights. She always used a measured communication style.

Lisa used three types of advocacy: disability expert and strategist--with her in-depth knowledge of policies, procedures and rights. The third was high profile--being highly involved and demanding the best services. She also fought seemingly incessantly for Nicole’s services and education, another characteristic of a high-profile style.

Each mother demonstrated the advocacy styles identified by Rehm et al. (2013) and Trainor (2010); however these styles did not facilitate effective advocacy most of the time. The mothers used different types of advocacy styles depending on factors such as the current relationship with involved school personnel and the level of negotiation necessary.

Involvement

Mothers had to maintain vigilance over their children’s education, being involved at all stages. This finding supports a similar finding by Lalvani & Hale (2015) which found vigilance was key to mothers’ involvement in their children’s programming. Mothers found effective advocacy included speaking up consistently and maintaining full engagement, a descriptor that aligns with research by Lalvani (2012) which found mothers’ advocacy was effective when they became a “squeaky wheel”; and spoke up with concerns and questions.

Mothers perceived negative interactions leading to serious conflicts as a “fight”. While the definition of fight connotes a battle, combat or struggle, mothers interpreted these interactions to be combative, sometimes verbally, and extreme struggle. The toll these negative interactions had on the mothers was extreme, leading to exhaustion and increased stress.

Along with the fights mothers experienced with school personnel, the constant involvement and vigilance became exhausting for the mothers and significantly increased their stress. Many needed to disengage for a bit in an effort of self-preservation, a finding supported by Rehm and colleagues’ (2013) discovery that after years of conflict, parents feel exhausted, overwhelmed and frustrated, leading to burn out. Other studies supported mothers’ increased stress from the process of advocating in general (Wang et al., 2004) and participating in IEP meetings (Burke et al., 2017), as they were often deficit based and highlighted the negative relationships mothers had with school personnel.

Negotiations

Mothers negotiated with the system for the services and programs they felt were important for their children, such as increased related services (i.e. speech-language therapy), placements, or specialized transition services. In order to facilitate negotiations, the mothers all learned the importance of gaining and using knowledge of special ed law, while focusing on the child's needs. This was supported by studies which showed parents were successful in negotiations when they used knowledge of law, focused on the child's needs and were persistent with requests (Rehm, 2002; Rehm & Rohr, 2002). However, mothers were not always successful even with their increased knowledge of the law. It was found that the mothers who were the most successful, engaged legal representation.

Legal Representation

While only two of the mothers secured legal counsel, this was an important finding, as these mothers were the most successful with their advocacy and negotiations after legal became involved. Rehm et al. (2013) found school districts perceived parents' skill with using legal counsel as a threat and therefore were more likely to defer to the parents' requests leading to successful negotiations. I did not interview school districts to determine if this was indeed the perception, it could be inferred, as these two mothers often were granted their requests from this point on, though it was never a smooth and simple negotiation process. Although these mothers found success with use of legal counsel, the consequence was further demise of the school-parent relationship.

Self-Education of Law

Each mother had to educate herself on special education law, either by researching or finding someone who was highly versed in the law to support her understanding. If the mothers had not done this self-education, their children would likely have not received the services, programming and placement they were entitled to as written in their IEPs. The descriptor of the need for mothers' self-education aligns with research by Leiter & Kraus (2004) and Trainor (2010), which speak to the most effective advocacy is that which parents have access to knowledge and a strong understanding of their rights and responsibilities, along with IEP components and process.

Capital

All of the mothers in this study had capital and used it at various stages to navigate their child's education, whether they were aware of this strategy or not. The three types of capital as identified by Bourdieu (1974): social, cultural and economic, will be discussed below.

Social Capital

Susan and Christine both used their social capital when their children were very young. Susan's social capital was used to quickly confirm a suspected diagnosis of autism. Christine's social capital was used to secure specific selection of services due to her best friend being the head OT for the county's Birth-to-Three Program. These findings support research which showed mothers used their capital to obtain the diagnoses they wanted, leading to specific selection of services (Lalvani & Hale, 2015; Trainor, 2010b).

All of the mothers developed relationships which increased their social capital. Susan, Angela and Lisa all formed close relationships with outside professionals, leading to direct support from their ABA therapists in the schools. Christine, Kim, Mary's social capital was based on the relationships with other parents, leading to support systems outside of school. These beneficial relationships are what make up social capital (Bourdieu, 1974).

One area of challenge all of the mothers experienced was the stress of IEP meetings, although these meetings were stressful for the mothers during different educational stages. Some of the mothers experienced feeling disempowered or not in equal partnership with the IEP team, as some of the team members demonstrated higher social capital with the networks and relationships they had with each other, leading to feeling of disconnect between the mothers and the team. This descriptor aligns with research by Trainor (2010b), which speaks to how mothers can feel disempowered during IEP decision-making when there is a differential between mothers who may not have much cultural and social capital and the other IEP team members who may have more social capital (Trainor, 2010b)

Cultural Capital

Mothers' cultural capital included understanding special education law and using technical educational language, knowledge learned from other parents (intersection of cultural and social capital) and mothers' educational backgrounds. Two of the mothers frequently used complex language and professional jargon, which helped their advocacy efforts and aligned with research by Trainor (2010b) who found mothers who used the technical language were more successful in their advocacy attempts. Mothers used their capital to learn more in order to more effectively advocate for their children's education. This finding is supported by Lalvani & Hale (2015) who found mothers have been shown to use their capital to learn about placements, evidence-based practices, and the law to become an effective advocate.

Further, several of the mothers developed relationships with other mothers of children with disabilities, increasing their knowledge of special education. This was called "hidden cultural capital" by (Trainor, 2010b, p. 259) and was supported in her study finding mothers who had this type of capital learned how better to navigate their children's educations.

Economic Capital

Mothers with the largest amount of economic capital used their knowledge of IDEA the most. This shows the intersection of cultural capital and economic capital in the process of advocacy. Mothers with the largest amount of social capital accessed the most support throughout their children's educational stages. No matter, there was still a power differential between school systems and mothers, whether mothers had greater power from the support of legal counsel or less power as is most often seen in the literature. As Trainor (2010) noted, having a lot of capital did not mean mothers had a lot of power. This was evident in my study's findings. However, these mothers with a lot of economic capital have been found to utilize outside resources to educate their children, especially when they do not fully trust or find competency with public school to meet their child's needs (Lake and Billingsley, 2000), as Susan, Lisa and Angela did for their children with the intensive therapies, tutoring and private school.

All of these mothers possessed all three types of capital, though in varying degrees. They all used it in different ways and at different stages. It was found that the mothers who had the most capital had access to the most resources, supporting Bourdieu's (1974) claim that people with a lot of different types of capital have access to other resources.

Conflicts with the Literature

One could look at the school district and assume because it was considered an affluent district with a strong reputation for general education students, it was providing high quality education for all children, including students with significant disabilities. In fact, four of the mothers lived in school districts considered to be affluent, and they were challenged to secure the services and programming they had expected. This contradicts Trainor (2010a) who claimed parents who have all three types of capital are more likely to have quality education for their children, with the mothers having all three types of capital. These mothers thought they were securing high quality education, yet they had to fight for their child's education and many times were not entirely successful.

In addition, whereas Ong-Dean (2009) found parents must have high levels of cultural and economic capital to effectively dispute school decision-makers, Mary had moderate levels and was able to effectively dispute Rachel's change of placement. The mothers with high levels of cultural and economic capital were only effective with their negotiations after they involved legal counsel, and at the demise of the relationship.

Moreover, Lalvani and Hale (2015) found although the system is designed to work against parents and protect school districts, parents with large amounts of capital used this to their advantage to access and secure the special education programming they desired. While many of the mothers in my study had large amounts of capital and used it to advocate for their child's education, it was not found that they were able to secure everything they desired, even with the negotiations and fights. Mothers were not entirely successful against the strength and resistance of the school system.

Theoretical Frameworks

Two theoretical frameworks were used in the analysis of this study: Bronfenbrenner's Ecological Systems theory and Educational Stages. Bronfenbrenner's theory offers an understanding of how mothers of children with significant disabilities function in the school system as a whole. It gives more explanation to the intricacies of their interactions with school personnel and experiences with the system. Educational Stages included the four major systemic stages 1) early childhood, 2) elementary school, 3) middle school, 4) high school, along with diagnosis, Birth-to-Three and Transition Services (ages 18-21). The educational stages supported the chronology along with intersecting with Bronfenbrenner's Ecological Systems to show patterns and trends.

Bronfenbrenner's Ecological Systems

Most of the parental advocacy took place at the meso-level, with parents advocating to school personnel to impact their individual child's education. Some advocacy took place at the macro-level, with parents advocating legislatively to impact system changes, through policy and lobbying, as supported by Krueger and colleagues' (2019) study that shows parents advocating for systems change at the macro-level. Mothers self-preservation happened at the micro-level with them having to disengage from their advocacy efforts to reduce stress. Finally, the intersection with the exo-system happened when mothers had to secure legal counsel to protect their child's rights to FAPE.

Educational Stages

Most strategies were implemented during middle and high school years when students became full-educated in self-contained classrooms when placement became more restrictive to a self-contained classroom. Three of the mothers had to implement strategies from the beginning of their child's education all the way through, rarely taking a break, such as Susan who had to use strategies of negotiating for more therapy when Kate was in Birth-to-Three. It seems to be that the mothers of the children with autism were the ones implementing strategies from the beginning, such as Angela had to implement strategies throughout Max's education. Although Christine had to negotiate placement and programming early on during Hannah's kindergarten year, her main advocacy and strategy use began in middle school. Kim did not start implementing strategies until Mariah was in middle school, though she was not satisfied with Mariah's programming during elementary school. Mary's advocacy started late in high school.

Intersection of Frameworks

The intersection of frameworks occurred mainly during middle and high school at the meso-level with mothers advocating strongly with school personnel. While advocacy happened at every stage and impacted each ecological system, all mothers intersected at this point of meso-middle-high school.

Importance to the Field

The research regarding the experience of mothers navigating the education for their child with a significant disability is lacking. The findings from this study will make a significant contribution to understanding how mothers see the process and how school personnel might facilitate bringing mothers in as meaningful partners so that we can improve the quality of educational outcomes for children with significant disabilities.

The findings are important to this field by adding mothers' voices to the literature, as historically parents' voices have been absent. The findings also add to the transparency of the challenge of providing truly individualized instruction for the number of students with disabilities in schools. This leads to the question of why do we have IEPs if a child's education is not truly individualized? Is it just a facade for the law? The conclusion and these questions shine light on the need for a reauthorization of IDEA to support societal and parent expectations with school's ability to meet those expectations.

Implications for Practice

The findings allow some talking points to determine possible changes to the trend for inclusion, strengthening partnerships and ultimately improving outcomes for students with significant disabilities. Action steps for schools and families are explained below, including offering professional and personal development, and collaborative opportunities.

Action Steps for Schools

Since the beginning, with the Education for All Handicapped Children Act (1975) through IDEA (2004), the law mandates the Least Restrictive Environment (LRE), which is often confused with inclusion. LRE is a principle of the law stating students with disabilities should be educated alongside non-disabled peers to the greatest extent appropriate, including access to general-education curriculum and extra-curricular activities, with supports necessary to achieve their goals. Inclusion, on the other hand, is a philosophy that all students, including those with disabilities, regardless of the severity, are educated fully in general education classrooms in their home school (Learning Disabilities Association of America, 2012). School systems have taken to the practice of inclusion regardless of what LRE is for a student and the mother's desire for the child's placement. By law, the IEP drives the student's placement, not individual preferences or long-time practices.

School systems' resistance to change remains deep-rooted, as evidenced by what is occurring in practice does not align with what is known about providing opportunities to learn for students with significant disabilities alongside their non-disabled peers (Ryndak et al., 2013). The trend for inclusion is rooted with good intention; however, my observations of the practice share Ryndak et al.'s finding of students with disabilities not being provided opportunities to learn. If school systems claim the student's IEP is indeed individualized, then it needs to follow its title and individualize for the child, including placement, as research shows that a student's placement is determined by severity of disability along with other demographics (Brock & Schaefer, 2015), instead of based on individual student needs. Providing opportunities to learn for students with significant disabilities most certainly will require intensive and ongoing training for teachers and staff, including administrators, to follow the law and do what is right for children by providing access to the least restrictive environment and offering a free and appropriate education. The long-term outcomes of these placements have not been determined or studied well-enough to produce informative and reliable evidence or direction.

It is imperative that schools provide ongoing professional development around inclusive mindsets and practices, so the exclusionary examples described do not persist. Book studies, guest speakers, role playing and discussion groups are all examples of ways to learn and promote inclusive mindset and best practices for including students with disabilities in extracurricular activities. As parents of non-disabled children may not have knowledge of or exposure to inclusion, hosting round tables and presentations on this topic could help to support a community mindset shift towards the inclusion of people with disabilities. Studies show that parents of non-disabled peers view parents of children with disabilities as expecting preferential treatment for their children at the deprivation of non-disabled children as (Kotler, 2014). Therefore, the importance of educating parents and families of non-disabled children with a growth mindset on inclusion and acceptance is imperative.

Ensuring that teachers, other educational professionals and parents of non-disabled students develop and maintain an understanding that students with disabilities are not taking away spots on teams or in performances, know the names of all students on their teams and in their clubs, and truly get to know the students in these extracurricular activities is essential to inclusive schools. At an IEP meeting, the local education agency representative (LEA), often an administrator or other educational professional, should know the student's name and something about the student. This offers dignity to the family and builds feelings of care and trust.

Funding and IEP drafting. When it comes to funding, schools are the experts on their budgets and ability to provide services within their means. Due to outdated laws and budget constraints, parents' demands may not be able to be met. However, the delivery of the message remains an area of conflict. The law is designed so parents and schools are working together to develop an IEP. While the IEP should be drafted in collaboration with the parent at the meeting, some parents are not aware of the original intention of collaborative drafting of the plan at the meeting and expect the draft to be completed beforehand as has been the practice. Therefore, education and communication around the collaborative drafting process will need to be presented. Schools should allow and welcome the parents as equal and meaningful partners on the child's IEP team, taking on a mindset of parent as expert of their child and a willingness to work and collaborate with the parent. The current mindset of parent versus school is rapt with contention instead of collaboration and a mindset of parent together with school. Transparency and disclosing options and information is key to rebuilding trust with parents, though it is likely the power balance between mothers and schools will never be even (Kotler, 2014).

Action Steps for Parents

Mothers in this study offered advice to parents of children with significant disabilities when it comes to interacting with school systems. First and foremost, they expressed to network with other families with children with significant disabilities. This leads to empowerment, trust and a feeling of community. Mothers stated the importance of educating oneself on special education law and best practices in education is paramount. While the amount of work this entails can be exhausting, it is necessary to ensure schools follow the law and a parent's educational goals for their child are strongly considered. At an IEP meeting, parents should bring a photo of their child to display, if the child is not in attendance. This can help the team to focus on the child and not simply words on a page. When it comes to working with educational professionals, the delivery of the message is important; Susan suggested whatever it takes, develop a friendly working relationship with the child's educational professionals because that leads to better collaboration.

Implications for Future Research

Because the participants from this study were all white, educated and from middle and upper middle-class socioeconomic backgrounds, further research should seek to include culturally and ethnically diverse participants, along with participants from lower socioeconomic backgrounds. This study focused on the perspectives of mothers, so future research should seek to include the perspectives of fathers and other caregivers. As this study's participants were from suburban districts, future research should include families from rural communities. In addition, research on the experiences of parents of children with less significant disabilities would be interested to see if there are differences with this study's findings. Future research also needs to focus on teacher and administrator preparation programs and how these programs promote and sustain partnerships with parents, including parents of children with disabilities.

Lake and Billingsley (2000) presented the idea of seeing something through a lens, meaning how one perceives something is dependent on the lens chosen. Therefore, it could be applied that how these mothers chose to see their schools and personnel was dependent on the lens they chose. Another way to look at this is from Brown's (2018) notion of positive intent, which assumes everyone is doing the best they can. If mothers and school personnel assume positive intent, would the conflict significantly decrease? Would trust increase and discord lessen? Future research on mothers of children with significant disabilities and school personnel regarding growth mindset around the notion of positive intent may help to improve interactions, strengthen partnerships and increase positive outcomes for students.

Limitations

The limitations to this study included a single type of school, half of participants from the same school district, and lack of diversity. I did not include other types of schools, such as private schools and segregated schools, though one mother had a positive experience with one year of private school kindergarten. Not including these types of schools limited the data, which may have given important insight into the experiences of mothers in these placements, including expectations, interactions, negotiations and involvement. Three of the mothers were from the same school district, in which their children attended the same high school, though not all attending and graduating at the same time; however, the three mothers all had different feelings including wanting entirely segregated programming, to wanting inclusive programming, to wanting a blend of the two. The mothers all identified as being white, had similar socioeconomic statuses, and all had at least a bachelor's degree. This study lacked diversity, including race and class. Therefore, I was not able to get at issues of race and class to determine access and programming decisions that align with the literature.

Another limitation was my lack of extended relationships with the mothers. I only interviewed the mothers once and though the data gathered was sufficient to answer my research question, it would have been ideal to interview the mothers several times to the point of data saturation. Had I been able to spend more time with these mothers, I would have established greater trust and deepened my relationships with them, which may have allowed for further exploration into their experiences and feelings. One question that presented itself after the data collection and review of the literature, is, how trusting are mothers initially? That question was not asked, nor answered from the data and therefore is a limitation of this study.

Conclusion

My initial conclusion was that even though mothers had capital, they still experienced immense challenges with effective advocacy leading to positive outcomes and partnerships with school personnel. However, it became clear to me the main problem was the disconnect between the school's compliance with IDEA and what the mothers wanted for their child's education. It was found that although mothers wanted the best services for their children, the schools were not able to provide these services due to budgetary constraints, lack of staff and training. However, schools were not able to use these factors as reasons to not provide requested services or programming. As was first coined during the seminal Supreme Court case, Rowley vs. Board of Education, the Chevy versus Cadillac debate where school districts must provide basic special education services and programming instead of the top-of-the-line, most expensive services and programming. While this analogy dates itself with the car make references, we can understand the meaning of what schools are required to provide versus what parents want them to provide. To bring this up to date, we could say Toyota versus Rolls-Royce. It is understandable that mothers would want the best for their children and make those requests. As decided in Endrew F. versus Douglas County, IEPs are to be developed under the expertise of school administrators, along with the input of the parents, to be appropriately ambitious with consideration of each child's unique needs. However, the term *appropriate* remains open to individual interpretation. While mothers want the Cadillac or the Rolls-Royce, schools are never able to provide, even if they want to. School administrators' hands are tied because of outdated legislation leading to lack of federal funding.

IDEA has not been revised since 2004 and I will argue that society's views have evolved as to how we educate children with disabilities, the expectations we have for people with disabilities and the opportunities available. People with disabilities are much more visible in our communities than they were even five years ago. School districts are developing new programming for transition services education and implementing teaching of realistic life skills to support independent living. In the last ten years, grassroots efforts such as the Spread the Word campaign reached thousands of schools to promote inclusion of people with intellectual and developmental disabilities. TV shows are including actors with disabilities and companies are using models with disabilities in their print ads. While society's inclusion and acceptance of these heightened expectations for people with disabilities, the law remains outdated. This outdated law impacts the funding schools receive from the federal government in order to provide much needed individualized services that students are entitled to by law. Society's views are supported and broadened by the expectations parents have for their children. No longer is it considered the ultimate success for a young adult with Down Syndrome to be a bagger at a grocery store and live in their parents' house the rest of their lives. It is now the ultimate success for this young adult to have a career doing data entry at a hospital and living independently in their own apartment. Positive outcomes are about expectations. And successful positive outcomes are because of high expectations and partnership between stakeholders.

How do we get participation and authentic parental input? First, the law needs to be reauthorized to reflect updated views and practices, therefore supporting funding for schools to provide needed services and programming. Second, parents and school personnel need to develop trusting, respectful and reciprocal relationships. This is done through transparency and frequent and open communication. Schools need to see parents as partners and not adversaries. After all, both have the same goal of ensuring positive outcomes for the child.

I sought to find how mothers navigated their child's education. It was determined that mothers used specific strategies, such as developing relationships, educating themselves on the law and best practices, and explicitly communicating using learned educational language. Mothers developed relationships with school personnel both organically with positive partnerships and strategically through frequent communication due to problems they experienced. For example, some mothers developed relationships with principals, directors of special education or superintendents based on level of need due to their requests not being granted at the lower administrative level. Mothers also used their capital for navigation, whether or not they were conscious of this strategy.

The results of this qualitative study provide evidence of the need for increasing meaningful parent participation in the process of developing and maintaining IEPs. Evidence of implications for schools and parents show the necessity to collaborate to meet needs of students along with ongoing professional development and improving communication to strengthen working relationships, while also advocating for updated laws to reflect increased expectations for positive outcomes.

References

Agran, M., Cavin, M., Wehmeyer M. W., & Palmer, S. (2006). Participation of students with moderate to severe disabilities in the general curriculum: The effects of the Self-Determined Learning Model of Instruction. *Research and Practice for Persons with Severe Disabilities, 31*, 230-241.

Agran, M., Jackson, L., Kurth, J. A., Ryndak, D., Burnette, K., Jameson, M., Zagona, A., Fitzpatrick, H., & Wehmeyer, M. (2020). Why aren't students with severe disabilities being placed in general education classrooms: Examining the relations among classroom placement, learner outcomes, and other factors. *Research and Practice for Persons with Severe Disabilities*, *45*(1), 4-13. doi:10.1177/1540796919878134

Alberto, P. A. & Troutman, A. C. (2009). *Applied Behavior Analysis for Teachers* (9th ed). New York, NY: Pearson.

Anderson, L. S. (2009). Mothers of children with special health care needs: Documenting the experience of their children's care in the school setting. *The Journal of School Nursing : The Official Publication of the National Association of School Nurses, 25*(5), 342-351. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19383837

Anderson, L. W., Jacobs, J., Schramm, S., & Splittgerber, F. (2000). School transitions: Beginning of the end or a new beginning? *International Journal of Educational Research, 33*, 235-339.

Angell, M. E., Stoner, J. B., & Shelden, D. L. (2009). Trust in educational professionals: Perspectives of mothers of children with disabilities. *Remedial and Special Education, 30*(3), 160-176.

Ballard, S. L., & Dymond, S. K. (2020). Addressing the general education curriculum in general education settings with students with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, *42*(3), 155-170. doi:10.1177/1540796917698832

Barnitt, V., Benner, S., Hayes, E., Reardon, R., Ryndak, D. L., & Weser, S. (2007). *Best practices for inclusive education: An assessment and planning tool for systemic change.* Tallahassee: Florida Department of Education.

Bell, A. J. (2005). "Oh yes, I remember it well!" Reflections on using the life-grid in qualitative interviews with couples. *Qualitative Sociology Review, 1*(1), 51–67.

Bellini S., & Akullian, J. (2007). A meta-analysis of video modeling and video self-modeling interventions for children and adolescents with autism spectrum disorders. *Exceptional Children, 73*, 264-287. doi:10.1023/B:JOBE.0000037626.13530.96

Berney, L., & Blane, D. (2003). The lifegrid method of collecting retrospective information from people at older ages. *Research Policy and Planning*, *21*(2), 13-22.

Blue-Banning, M., Summers, J. A., Frankland, H. C., Lord Nelson, L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, *70*, 167-184.

Board of Education v. Rowley, 458 U.S. 176 (1982).

Bornstein, M. H., & Cheah, C. S. (2006). The place of culture and parenting in the ecological contextual perspective on developmental science. In K. H. Rubin & O. B. Chung (Eds.) *Parenting beliefs, behaviors, and parent-child relations: A cross-cultural perspective* (4). Taylor & Francis Group.

Bourdieu, P. (1974). Cultural reproduction and social reproduction. In R. Brown (Ed.), *Knowledge, education, and cultural change.* Tavistock.

Bourdieu, P. (2011). The forms of capital. In T. Kaposy & I. Szeman (Eds.), *Cultural theory: An anthology* (pp. 81-93). Wiley. (Original work published 1986)

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Brock, M. E. & Schaefer, J. M. (2015). Location matters: Geographic location and educational placement of students with developmental disabilities. *Research and Practice for Persons with Severe Disabilities 40*(2), 154-164.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychology, 32*, 515-531.

Brookfield, S. D. (2017). *Becoming a critically reflective practitioner.* (2nd ed.). John Wiley & Sons, Incorporated.

Browder, D. M., Ahlgrim-Delzell, L., Spooner, F., Mims, P. J., & Baker, J. N. (2009). Using time delay to teach literacy to students with severe developmental disabilities. *Exceptional Children, 75*, 343-364.

Browder, D. M., Jimenez, B. A., & Trela, K. (2012). Grade-aligned math instruction for secondary students with moderate intellectual disability. *Education and Training in Autism and Development Disabilities, 47*, 373-388. doi:10.1080/09362835.2013.802236

Browder, D. M., Wood, L., Thompson, J., Ribuffo, C. (2014). *Evidence-based practices for students with severe disabilities* (Document No. IC-3). Retrieved from University of Florida, Collaboration for Effective Educator, Development, Accountability, and Reform Center website: http://ceedar.education.ufl.edu/tools/innovation-configurations/

Brown, B. (2018). *Dare to lead: Brave work. Tough conversations. Whole hearts.* Random House.

Burgess, N., Harris-Britt, A., Boyer, E., & Marks-Frey, M. (2014). *African American mothers of children with autism and their experiences of receiving support: A generic qualitative study*, ProQuest Dissertations and Theses.

Burke, M. M., Chan, N., & Neece, C. L. (2017). Parent perspectives of applying mindfulness-based stress reduction strategies to special education. *Intellectual and Developmental Disabilities*, *55*(3), 167-180. doi:10.1352/1934-9556-55.3.167

Burke, M. M., & Hodapp, R. M. (2014). Relating stress of mothers of children with developmental disabilities to family-school partnerships. *Intellectual and Developmental Disabilities*, *52*, 13-23. http://dx.doi.org/10.1352/1934-9556-52.1.13

Burke, M. M., & Hodapp, R. M. (2016). The nature, correlates, and conditions of parental advocacy in special education. *Exceptionality*, *24*, 137-150. http://dx.doi.org/10.1080/09362835.2015.1064412

Burke, M. M., Meadan-Kaplansky, H., Patton, K. A., Pearson, J. N., Cummings, K. P., & Lee, C. (2018). Advocacy for children with social-communication needs: Perspectives from parents and school professionals. *The Journal of Special Education*, *51*(4), 191-200. doi:10.1177/0022466917716898

Carson, C. (2015). Rethinking special education's "Least Restrictive Environment" requirement. *Michigan Law Review, 113*(8), 1397-1426. Retrieved from www.jstor.org/stable/24770829

Carter, E., & Hughes, C. (2006). Including high school students with severe disabilities in general education classes: Perspectives of general and special educators, paraprofessionals, and administrators. *Research and Practice for Persons with Severe Disabilities*, 2, 174-185. doi:10.1177/154079690603100209

Carter, E. W., Brock, M. E., Bottema-Beutel, K., Bartholomew, A., Boehm, T. L., & Cease-Cook, J. (2013). Methodological trends in secondary education and transition research: Looking backward and moving forward. *Career Development and Transition for Exceptional Individuals, 36*(1), 15-24. doi:10.1177/2165143413475659

Carter, E. W., Sisco, L. G., Chung, Y. & Stanton-Chapman, T. L. (2010). Peer interactions of students with intellectual disabilities and/or autism: A map of the intervention literature. *Research and Practice for Persons with Severe Disabilities, 35*, 63-79.

Cartledge, G., Gardner III, R., & Ford, D. Y. (2009). *Diverse learners with exceptionalities: Culturally responsive teaching in the inclusive classroom*. Pearson Learning Solutions.

Charmaz, K. (2008). Constructionism and the grounded theory. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of Constructionist Research* (pp. 397-412). The Guilford Press. Retrieved from http://www.sxf.uevora.pt/wp-content/uploads/2013/03/Charmaz_2008-a.pdf

Connell, S. L. (2016). *Why parents, in the Penn Valley Area School District, choose cyber charter or charter schools over the local public school district.* Retrieved from ProQuest Dissertations Publishing. 10296960.

Connor, D. J., & Ferri, B. (2007). The conflict within: Resistance to inclusion and other paradoxes in special education. *Disability and Society*, *22*(1), 63-77.

Council for Exceptional Children. (2015). *What every special educator must know: Professional ethics and standards.* (7th ed.). Council for Exceptional Children.

Covert, S. B. (1995). Supporting families. In J. Nisbet (Ed.), *Natural supports in school, at work, and in the community for people with severe disabilities* (pp. 121-163). Brookes.

Coyne, P., Pisha, B., Dalton, B., Zeph, L. A., & Smith, N. C. (2012). Literacy by design: A Universal Design for Learning approach for students with significant intellectual disabilities. *Remedial and Special Education, 33*(3), 162-172.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches*. Los Angeles.

Creswell, J. W. & Poth, C. N. (2018). *Qualitative inquiry and research design.* Sage.

Currie, J. & Kahn, R. (2012). Children with disabilities: Introducing the issue. *The Future of Children, 22*(1), 3-11.

Daniel R. R. v. State Board of Education, 874 F.2d 1036 (5th Cir. 1989).

Delano, M. E., Keefe, L. & Perner, D. (2008-2009). Personnel preparation: Recurring challenges and the need for action to ensure access to general education. *Research and Practice for Persons with Severe Disabilities, 33-34*(4-1), 232-240. doi:10.2511/rpsd.33.4.232

Democracy Disability and Society Group. (2003). *Medical model of disability*. Taxi driver training pack. http://www.ddsg.org.uk/taxi/medical-model.html

Democracy Disability and Society Group. (2003). *Social model of disability*. Taxi driver training pack. http://www.ddsg.org.uk/taxi/social-model.html

Dhuey, E. & Lipscomb, S. (2011). Funding Special Education by Capitation: Evidence from State Finance Reforms, Education, Finance and Policy, 6(2), p. 168-201.

Dupre, A. P. (1997). Disability and the public schools: The case against "inclusion". *Washington Law Review, 72*(775), 775-858.

Downing, J. E. (2005). *Teaching literacy to students with significant disabilities: Strategies for the k-12 inclusive classroom.* Corwin Press.

Downing, J. E., & Peckham-Hardin, K. D. (2007). Inclusive education: What makes it a good education for students with moderate to severe disabilities? *Research and Practice for Persons with Severe Disabilities*, *32*, 16–30.

Education for All Handicapped Children Act of 1975, Publ. L. No. 94-142. (1975). https://uscode.house.gov/statutes/pl/94/142.pdf

Elbaum, B., Blatz, E. T., Rodriguez, R. J. (2016). Parents' experiences as predictors of state accountability measures of school's facilitation of parent involvement. *Remedial and Special Education*, *37*(1), 15-27.

Endrew F. v. Douglas County School District. (n.d.). *Oyez*. Retrieved June 22, 2020, from https://www.oyez.org/cases/2016/15-827#!

Erwin, E. J., & Soodak, L. C. (1995). I never knew I could stand up to the system: Families' perspectives on pursuing inclusive education. *The Journal of the Association for Severe Handicaps*, *20*, 136-146.

Evans, I. M., Salisbury, C. L., Palombaro, M. M., Berryman, J., & Hollowood, T. M. (1992). Peer interactions and social acceptance of elementary-age children with severe disabilities in an inclusive school. *Journal of the Association for Persons with Severe Handicaps, 17*, 205-212.

Fisher, D., Pumpian, I., & Sax, C. (1998). Parent and caregiver impressions of different educational models. *Remedial and Special Education*, *19*, 173-180. doi:10.1177/074193259801900305

Fitzgerald, J. L., & Watkins, M. W. (2006). Parents' rights in special education: The readability of procedural safeguards. *Exceptional Children*, 72, 497-510.

Frattura, E., & Capper, C. A. (2006). Segregated programs versus integrated comprehensive service delivery for all learners: Assessing the differences. *Remedial and Special Education, 27*, 355-364.

Gant, R. (1977). Retrospective interviews: A technique for rural studies. *Teaching Geography, 4*(2), 167-169.

Goodman, M., Finnegan, R., Mohadjer, L., Krenzke, T., & Hogan, J. (2013). *Literacy, numeracy, and problem solving in technology rich environments among U.S. adults: Results from the Program for the International Assessment of Adult Competencies 2012.* U. S. Department of Education. https://nces.ed.gov/pubs2014/2014008.pdf

Groenewald, C. & Bhana, A. (2015). Using the lifegrid in qualitative interviews with parents and substance abusing adolescents. *Qualitative Social Research, 16*(3), Art. 24.

Hall, L. J. (1994). A descriptive assessment of social relationships in integrated classrooms. *Journal of the Association for Persons with Severe Handicaps, 19*, 302-313.

Harry B. (1992). Restructuring the participation of African-American parents in special education. *Exceptional Children*, *59*(2), 123–132.

Harry, B., & Klingner, J. (2006). *Why are so many minority students in special education?* Teachers College Press.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*, 629-642. http://dx.doi.org/10.1007/s10803-012-1604-y

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: parent voice and advocacy in special educational decision making. *British Journal of Special Education, 33*(3), 148-157.

Hetherington, S. A. (2012). They think we don't have the knowledge: The intersection of autism and race, ProQuest LLC.

Heumann, J. E., & Hehir, T. (November 23, 1994). Questions and answers on the least restrictive environment requirements of the Individuals with Disabilities Education Act. Retrieved from https://www.wrightslaw.com/law/osep/lre.osep.memo.1994.1123.pdf

Horvat, E. M., Weininger, E. B., & Lareau, A. (2003). From social ties to social capital: Class differences in the relations between schools and parent networks. *American Educational Research Journal*, *40*(2), 319-351.

Hoy, W. K., & Tschannen-Moran, M. (1999). Five faces of trust: An empirical confirmation in urban elementary schools. *Journal of School Leadership, 9*(3), 184-208.

Hunt, P., McDonnell, J., & Crockett, M. A. (2012). Reconciling an ecological curricular framework focusing on quality of life outcomes with the development and instruction of standards-based academic goals. *Research and Practice for Persons with Severe Disabilities, 37*, 139-152.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004). Retrieved from https://sites.ed.gov/idea/about-idea/

Jackson, A. C., Liang, R. P., Frydenberg, E., Higgins, R. O., & Murphy, B. M. (2016) Parent education programmes for special health care needs children: A systematic review. *Journal of Clinical Nursing, 25*, 1528-1547.

Jimenez, B. A., Browder, D. M., Spooner, F. & Dibiase, W. (2012). Inclusive inquiry science using peer-mediated embedded instruction for students with moderate intellectual disability. *Exceptional Education, 78*, 301-317.

Jorgensen, C. M., & Lambert, L. (2012). Inclusion means more than just being "in": Planning full participation of students with intellectual and other developmental disabilities in the general education classroom. *International Journal of Whole Schooling*, *8*(2), 21-36.

Kawulich, B. (2012). Selecting a research approach: Paradigm, methodology and methods. In Wagner, C., Kawulich, B., & Garner, M. (Eds.), *Doing social research: A global context* (51-61). McGraw Hill.

Keen, D., Brannigan, K. L., & Cuskelly, M. (2007). Toilet training for children with autism: The effects of video modeling category. *Journal of Developmental and Physical Disabilities, 19*(4), 291-303.

Kirk, S. A. (1984). Introspection and prophecy. In B. Blatt & R. J. Morris (Eds.), *Perspectives in special education: Personal Orientations* (pp. 25-55). Scott Foresman.

Kleinert, H., Towles-Reeves, E., Quenemoen, R., Thurlow, M., Fluegge, L., Weseman, L., & Kerbel, A. (2015). Where students with the most significant cognitive disabilities are taught: Implications for general curriculum access. *Exceptional Children, 81*, 312-328.

Kliebenstein, M. A. & Broome, M. E. (2000). School re-entry for the child with chronic illness: Parent and school personnel perceptions. *Pediatric Nursing, 26*, 579–584.

Kotler, M. A. (2014). Distrust and disclosure in special education law. *Penn State Law Review, 119*(2), 485-552.

Krueger, K., Cless, J. D., Dyster, M., Reves, M., Steele, R., & Goff, B. S. N. (2019). Understanding the systems, contexts, behaviors and strategies for parents advocating for their children with Down Syndrome. *Intellectual and Developmental Disabilities*, *57*, 146-157. doi:10.1352/1934-9556-57.2.146.

Kruger, J., Burrus, J., & Kressel, L. M. (2009). Between a rock and a hard place: Damned if you do, damned if you don't. *Journal of Experimental Social Psychology, 45*(6), 1286-1290.

Kurz, A., Elliot, S. N., Lemons C. J., Zigmond, N., Kloo, A., & Kettler, R. J. (2014). Assessing opportunity-to-learn for students with disabilities in general and special education classes. *Assessment for Effective Intervention, 40,* 24-39.

Lalvani, P. (2012). Parents' participation in special education in the context of implicit educational ideologies and socioeconomic status. *Education and Training in Autism and Developmental Disabilities*, *47*(4), 474-486.

Lalvani, P. (2013). Land of misfit toys: Mothers' perceptions of educational environments for their children with Down Syndrome. *International Journal of Inclusive Education*, *17*(5), 435-448.

Lalvani, P., & Hale, C. (2015). Squeaky wheels, others from hell, and CEOs of the IEP: Parents, privilege, and the "fight" for inclusive education. *Understanding and Dismantling Privilege. 5*(2).

Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities, 26*(2), 121-139. doi: 10.1007/s10912-005-2914-2

Learning Disabilities Association of America. (2012, June). *Full inclusion of all students with learning disabilities in the regular education classroom.* https://ldaamerica.org/advocacy/lda-position-papers/full-inclusion-of-all-students-with-learning-disabilities-in-the-regular-education-classroom/

Leiter, V. & Krauss, M. W. (2004). Claims, barriers, and satisfaction. *Journal of Disability Policy Studies*, *15*(3), 135-146.

Leko, M. M., Brownell, M. T., Sindelar, P. T., & Kiely, M. T. (2015). Envisioning the future of special education personnel preparation in a standards-based era. *Exceptional Children*, *82*, 25-43. doi:10.1177/0014402915598782

Leyser, Y., & Kirk, R. (2004). Evaluating inclusion: An examination of parent views and factors influencing their perspectives. *International Journal of Disability, Development & Education*, *51*(3), 271-285.

Lian, M.-G. J., & Fontánez-Phelan, S. M. (2001). Perceptions of Latino parents regarding cultural and linguistic issues and advocacy for children with disabilities. *Journal of the Association for Persons with Severe Handicaps*, *26*, 189-194.

Lignugaris-Kraft, B., Sindelar, P. T., McCray, E., & Kimerling, J. (2014). The "wicked question" of teacher education effects and what to do about it. In P. Sindelar, E. McCray, M. T. Brownell, & B. Lignugaris-Kraft (Eds.), *Handbook of research on special education teacher preparation* (pp. 461-471). Routledge.

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. Sage Publications.

Lipsky, D. K., & Garner, A. (1997). *Inclusion and school reform: Transforming America's classrooms*. Brookes.

Manago, B., Davis, J. L. & Goar, C. (2017). Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Science & Medicine, 184*, 169-177.

Mandic, C. G., Rudd, R., Hehir, T., & Acevedo-Garcia, D. (2012). Readability of special education safeguards. *The Journal of Special Education*, *45*(4), 195-203.

Marcenko, M. O., & Myers, J. C. (1991). Mothers of children with developmental disabilities: Who shares the burden? *Family Relations*, *40*(2), 186-190. doi:10.2307/585481

Martin, J. E. Van Dyke, J., Greene, B. A., Gardner, J. E. Christensen, W. R., Woods, L. L., & Lovett, D. L. (2006). Direct observation of teacher-directed IEP meetings: Establishing the need for student IEP meeting instruction. *Exceptional Children, 72*, 187-200.

Matzen, K., Ryndak, D., Nakao, T. (2010). Middle school teams increasing access to general education for students with significant disabilities: Issues encountered and activities observed across contexts. *Remedial and Special Education*, *31*, 287-304. doi:10.1177/0741932508327457

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, *35*(4), 833-848.

Mechling, L. C., Gast, D. L., Seid, N. H. (2009). Using a personal digital assistant to increase independent task completion by students with autism spectrum disorder. *Journal of Autism Developmental Disorders 39*(10), 1420-1434.

Mehan, H., Hertweck, H., & Meihls, J. (1986). *Handicapping the Handicapped*. Stanford University Press.

Merriam, S. and Tisdell, E. (2016). *Qualitative research*. 1st ed. Jossey-Bass.

Meyer, L. H., Eichinger, J. & Park-Lee, S. (1987). A validation of program quality indicators in educational services for students with severe disabilities. *The Journal of the Association for Persons with Severe Handicaps, 12*, 251-263. doi:10.1177/154079698701200401

Miller, K. L., McKeever, P., Coyte, P. (2003). Recruitment issues in healthcare research: The situation in home care. *Health and Social Care in the Community, 11*(2), 111-123.

Morningstar, M. E., Kurth, J. A., & Johnson, P. E. (2017). Examining national trends in educational placements for students with significant disabilities. *Remedial and Special Education, 38*(1), 3-12.

Morse, T. E., & Schuster, J. W. (2004). Simultaneous prompting: A review of literature. *Education and Training in Developmental Disabilities, 39*, 153-168.

Moustakas, C. E. (1994). Phenomenological research methods. Sage Publications, Inc.

National Alliance for Caregiving. (2009). *Caregiving in the U.S.* http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

National Council on Disabilities. (1989). *The education of students with disabilities: Where do we stand?* Washington, DC: U.S. Government Printing Office.

Newman, L., Wagner, M., Huang, T., Shaver, D., Knokey, A.-M., Yu, J., Contreras, E., Ferguson, K., Greene, S., Nagle, K., & Cameto, R. (2011). *Secondary school programs and performance of students with disabilities: A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2).* (NCSER 2012-3000). Washington DC: U.S. Department of Education, National Center for Special Education Research.

No Child Left Behind Act of 2001, 20 U.S.C. *70 § 6301 et seq.* (2002).

Noy, C. (2008). Sampling knowledge: The hermeneutics of snowball sampling in qualitative research. *International Journal of Social Research Methodology, 11*(4), 327-344.

O’Connor, M., Howell-Meurs, S., Kvalsvig, Al, & Goldfeld, S. (2014). Understanding the impact of special health care needs on early school functioning: A conceptual model. *Child: care, health and development, 41*(1), 15-22.

Oberti v. Board of Education of Clementon, 995 F.2d 1204 (3rd Cir. 1993).

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, *31*, 1-12.

Office of Special Education and Rehabilitative Services. (2015). *Dear colleague letter: Significant guidance on Free and Appropriate Public Education (FAPE).* Retrieved from https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/guidance-on-fape-11-17-2015.pdf

Ong-Dean, C. (2009). *Distinguishing disability: Parents, privilege, and special education*. University of Chicago Press.

Palmer, D., Borthwick-Duffy, S., Widaman, K., & Best, S. (1998). Influences on parent perceptions of inclusive practices for their children with mental retardation. *American Journal on Mental Retardation, 3*, 272-287.

Palmer, D. S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. *Exceptional Children, 67*(4), 467-484.

Park, J., Turnbull, A. P., & Park, H.-S. (2001). Quality partnerships in service provision for Korean American parents of children with disabilities: A qualitative inquiry. *Journal of the Association for Persons with Severe Handicaps*, *26*(3), 158.

Parry, O., Thomson, C., & Fowkes, G. (1999). Life course data collection: Qualitative interviewing using the life grid. *Sociological Research Online*, *4*(2), 102-112.

Patel, M. X., Doku, V., & Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment, 9*, 229-238.

Pence, A. R., & Dymond, S. K. (2016). Teachers' beliefs about the participation of students with severe disabilities in school clubs. *Research & Practice for Persons with Severe Disabilities*, *41*(1), 52-68.

Pfeiffer, D. (1999). The categorization and control of people with disabilities. *Disability and Rehabilitation, 21*(3), 106-107.

Prizant, B. M. (2008). Treatment options and parent choice: An individualized approach to intervention. *Autism Spectrum Quarterly, Winter*, 34-37.

Rehm, R. S. (2002). Creating a context of safety and achievement at school for children who are medically fragile/technology dependent. *Advances in Nursing Science*, *24*(3), 71-84.

Rehm, R. S., Fisher, L. T., Fuentes-Afflick, E., Chesla, C. A. (2013). Parental advocacy styles for special education students during the transition to adulthood. *Qualitative Health Research*, *23*(10), 1377-1387.

Rehm, R. S., & Rohr, J. A. (2002). Parents', nurses', and educators' perceptions of risks and benefits of school attendance by children who are medically fragile/technology dependent. *Journal of Pediatric Nursing*, *17*(5), 345-353. doi:10.1053/jpdn.2002.127174

Richardson, J. C., Ong, B. N., Sim, J., & Corbett, M. (2009). Begin at the beginning...Using a lifegrid for exploring illness experience. *Social Research Update*, *57*, 1-4.

Ruppar, A. L., & Gaffney, J. S. (2011). Individualized education program team decisions: A preliminary study of conversations, negotiations, and power. *Research and Practice for Persons with Severe Disabilities, 36*, 11-22.

Ruppar, A. L., Gaffney, J. S., & Dymond, S. K. (2015). Influences on teachers' decisions about literacy for secondary students with severe disabilities. *Exceptional Children, 81*(2), 209-226.

Ruppar, A. L., Allcock, H., & Gonsier-Gerdin, J. (2017). Ecological factors affecting access to general education content and contexts for students with significant disabilities. *Remedial and Special Education, 38*(1), 53-63.

Ryndak, D. L., Jackson, L., & Billingsley, F. (2000). Defining school inclusion for students with moderate to severe disabilities: What do experts say? *Exceptionality*, *8*, 101–116.

Ryndak, D. L., Jackson, L. B., & White, J. M. (2013). Involvement and progress in the general curriculum for students with extensive support needs: K-12 inclusive-education research and implications for the future. *Inclusion, 1*, 28-49.

Ryndak, D., Storch, J., & Hoppey, D. (2008). One family's perspective of their experiences with school and district personnel over time related to inclusive educational services for a family member with significant disabilities. *International Journal of Whole Schooling*, *4*(2), 29-51.

Schneider, M., Marschall, M., Teske, P. & Roch, C. (1998). School choice and culture wars in the classroom: What different parents seek from education. *Social Science Quarterly, 79*(3), 489-501.

Section 504 of the Rehabilitation Act of 1973, 34 C.F.R. Part 104.

Serres, S. A., & Simpson, C. (2013). Serving educational pie: A multidisciplinary approach to collaborating with families. *Children and Schools*, *35*(3), 189-191.

Shelden, D. L., Angell, M. E., Stoner, J. B., & Roseland, B. D. (2010). School principals' influence on trust: Perspectives of mothers of children with disabilities. *The Journal of Educational Research*, *103*, 159-170. doi:10.1080/00220670903382921

Shuffelton, A. (2017). Parental involvement and public schools: Disappearing mothers in labor and politics. *Studies in Philosophy and Education, 36*, 21–32. https://doi-org.ezproxy.lib.uwm.edu/10.1007/s11217-016-9537-0

Shyman, E. (2016). The reinforcement of ableism: Normality, the medical model of disability, and humanism in applied behavior analysis and ASD. *Intellectual and Developmental Disabilities, 54*(5) 366–376.

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, *38*, 18-29.

Soodak, L. C., & Erwin, E. J. (2000). Valued member or tolerated participant: Parents' experiences in inclusive early childhood settings. *The Journal of the Association for Persons with Severe Handicaps*, *25*, 29-44.

Stoner, J. B., & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and other Developmental Disabilities*, *21*(3), 177-189.

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and educational professionals. *Focus on Autism and Other Developmental Disabilities*, *20*(1), 39-51. doi:10.1177/10883576050200010401

Strully, J. L., & Strully, C. (1996). Friendship as an educational goal: What we have learned and where we are headed. In S. Stainback & W. Stainback (Eds.), *Inclusion: A guide for educators* (pp. 141-154). Brookes.

Swaminathan, R. & Mulvihill, T. A. (2019). Learning to ‘site-see’: Place-reflexivity as a methodological tool for qualitative researchers. *International Journal of Qualitative Studies in Education*, *32*(8), 982-997. doi:10.1080/09518398.2019.1635280

Taub, D. A., McCord, J. A., & Ryndak, D. L. (2017). Opportunities to learn for students with extensive support needs: A context of research-supported practices for all in general education classes. *The Journal of Special Education*, *51*(3), 127–137.

Townsend, A., Bland-Stewart, L., Lucker, J., McNeilly, L., Payne, K., & Wright-Harp, W. (2012). An ethnographic investigation of African American mothers of children with autism spectrum disorders, ProQuest Dissertations and Theses.

Trainor, A. A. (2010a). Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital. *Remedial and Special Education*, *31*, 34-47.

Trainor, A. A. (2010b). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly*, *41*(3), 245-263.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues*, *12*, 211-228. doi:10.1177/019251391012002005

Tucker, V., & Schwartz, I. (2013). Parents’ perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health*, *5*, 3–14. doi 10.1007/s12310-012-9102-0

Turnbull, R., & Turnbull, A. (2001). Families, professionals, and exceptionality: Collaborating for empowerment (4th ed.). Merrill Prentice Hall.

Turnbull, R., & Turnbull, A. (2015). Looking backward and framing the future for parents' aspirations for their children with disabilities. *Remedial and Special Education*, *36*(1), 52-57.

U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs. (2020). *Forty-first annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2017.* Author.

van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. State University of New York Press.

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers. J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities*, *29*, 144-155. doi:10.2511-/rpsd.29.2.144

Webster, R. I., Majnemer, A., Platt, R. W., & Shevell, M. I. (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology*, *23*, 32-38.

Wehman, P. (2013). Transition from school to work: Where are we and where do we need to go? *Career Development and Transition for Exceptional Individuals*, *36*, 58-66.

Wehmeyer, M. (1992). Self-determination: Critical skills for outcome-oriented transition services. *Journal for Vocational Special Needs Education*, *15*, 3-7.

Wehmeyer, M. L., Palmer, S. B., Agran, M., Mithaug, D. E., & Martin, J. E. (2000). Promoting causal agency: The Self-Determined Learning Model of Instruction. *Exceptional Education, 66*, 439-453.

Wehmeyer, M., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, *33*, 3-12.

Wehmeyer, M., Shogren, K., Palmer, S., Williams-Diehm, K., Little, T., & Boulton, A. (2012). The impact of the Self-Determined Learning Model of Instruction on student self-determination. *Exceptional Children, 78*, 135-153.

Westling, D. L., & Fox, L. (2009). *Teaching students with severe disabilities* (4th ed.). Pearson.

Woods, A. D., Morrison, F. J., & Palincsar, A. S. (2018). Perceptions of communication practices among stakeholders in special education. *Journal of Emotional and Behavioral Disorders*, *26*(4), 209-224. doi:10.1177/1063426617733716

Wisconsin Department of Public Instruction. (2019). Special education and school-age parents aid. Retrieved from https://dpi.wi.gov/sfs/aid/special-ed/sped-sap/overview

Wiseley, K. S. (2019, Nov. 20). *Parent's choice of an educational setting for their child with a significant disability* [Presentation of original research]. Candidate Research Presentation, University of Wisconsin-Parkside, Kenosha, WI, United States.

Wolery, M., Ault, M. J., & Doyle, P. M. (1992). *Teaching Students with Moderate to Severe Disabilities: Use of Response Prompting Strategies*. Longman Pearson.

Wolfensberger, W. (1977). *A balanced multi-component advocacy/protection schema*. Canadian Association for the Mentally Retarded.

Woodgate, R. L., Edwards, M. & Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science & Medicine, 75*, 1912-1920. doi: http://dx.doi.org/10.1016/j.socscimed.2012.07.037

Young, K. (2011). Institutional separation in schools of education: Understanding the functions of space in general and special education teacher preparation. *Teaching and Teacher Education*, *27*(2), 483-493.

Zeitlin, V. M. & Curcic, S. (2013). Parental voices on individualized education programs: Oh! IEP meeting tomorrow? Rum tonight! *Disability and Society, 29*(3), 373-387. doi: 10.1080/09687599.2013.776493

Zionts, L. T., Zoints, P., Harrison, S., & Bellinger, O. (2003). Urban African American families' perceptions of cultural sensitivity within the special education system. *Focus on Autism & Other Developmental Disabilities*, *18*(1), 41.

Appendix A

Recruitment Email

Dear [*insert name*],

Thank you for your interest in participating in my research study for my doctoral dissertation about how parents with children with significant disabilities negotiate the education of their children from diagnosis through age 21. I am a doctoral student from the Department of Teaching and Learning at the University of Wisconsin - Milwaukee.

If you decide to participate in this study, you will be interviewed twice by the primary researcher. In the first interview you'll be asked to share your experience of your child's education from entry in the school system through age 21. You'll be asked about what happened, who was involved and the feelings you had at various points and transitions during your child's education. The second interview will be a follow up for clarification or further questions to better understand your experience. Each interview will be 45-60 minutes. I would like to audio record your interviews and then I'll use the information to support my understanding of your experiences. Your information will remain confidential. The information may be used in future studies with all identifying information removed.

Remember, your participation is voluntary. You can choose to be in the study or not. If you'd like to participate or have any questions about the study, please email or contact me at xxx@uwm.edu or xxx-xxx-xxxx.

Thank you very much.

Sincerely,
Kristin Wiseley

Appendix B

Consent Form

Study title	How do parents of children with significant disabilities negotiate the education of their children from diagnosis through age 21 and to what extent they involve themselves in the process?
Researcher	Kristin Wiseley, Ph.D. Candidate / MS / Department of Teaching and Learning

I'm inviting you to participate in a research study. Participation is completely voluntary. If you agree to participate now, you can always change your mind later. There are no negative consequences, whatever you decide.

What is the purpose of this study?

I want to understand the experiences of parents of children with significant disabilities in how they negotiate the education of their children from diagnosis through age 21.

What will I do?

You will be interviewed by the primary researcher. You'll be asked to share your experience of your child's education from entry in the system through age 21. You'll be asked about what happened, who was involved and the feelings you had at various points and transitions during your child's education. The second interview will be a follow up for clarification or further questions to better understand your experience. Each interview will be 45-60 minutes.

Risks

Possible risks	**How we're minimizing these risks**
Some questions may be personal or upsetting	You can skip any questions you don't want to answer. You can take a break if you become distressed.

Breach of confidentiality (your data being seen by someone who shouldn't have access to it)	• All identifying information is removed and replaced with a study ID. • I'll store voice recordings on a password-protected and face-recognition protected phone. • I'll store electronic data (emails, transcriptions) on an encrypted computer. • I'll store all paper data in a locked filing cabinet in a locked office. • I'll keep your identifying information separate from your research data, but we'll be able to link it to you by using a study ID.

There may be risks we don't know about yet. Throughout the study, I'll tell you if we learn anything that might affect your decision to participate.

Other Study Information

Possible benefits	• Helping understand more about creating meaningful partnerships between parents and schools to improve educational outcomes for students with significant disabilities
Estimated number of participants	10
How long will it take?	120 minutes
Costs	You'll pay for your own transportation and parking if necessary.
Compensation	None
Future research	Data will be kept for use in possible future studies. De-identified (all identifying information removed) data may be shared with other researchers. You won't be told specific details about these future research studies.
Recordings	I will record you. The recordings will be used for interview transcripts. The recording is optional.

What if I am harmed because I was in this study?

If you're harmed from being in this study, let us know. If it's an emergency, get help from 911 or your doctor right away and tell us afterward. We can help you find resources if you need psychological help. You or your insurance will have to pay for all costs of any treatment you need.

Confidentiality and Data Security

We'll collect the following identifying information for the research: name, phone number and email address. This information is necessary to be in contact with you during the interviewing process.

Where will data be stored?	Voice recordings will be stored on my password and face-recognition protected phone. All other data will be stored on my computer, which is password and fingerprint protected.
How long will it be kept?	Voice recordings will kept until approximately 12/31/20 and then discarded. Other data will be kept an indefinite amount of time.

Who can see my data?	**Why?**	**Type of data**
The researchers	To conduct the study and analyze the data	Coded (names removed and labeled with a study ID)
The IRB (Institutional Review Board) at UWM The Office for Human Research Protections (OHRP) or other federal agencies	To ensure we're following laws and ethical guidelines	Coded (names removed and labeled with a study ID)
Anyone (public)	If we share our findings in publications or presentations	• Aggregate (grouped) data • De-identified (no names, birthdate, address, etc.) • If I quote you, I'll use a pseudonym (fake name)

Mandated Reporting

We are mandated reporters. This means that if we learn or suspect that a child is being abused or neglected, we're required to report this to the authorities.

Contact information:

For questions about the research	Kristin Wiseley	xxx-xxx-xxx; xxx@uwm.edu
For questions about your rights as a research participant	IRB (Institutional Review Board; provides ethics oversight)	xxx-xxx-xxxx / xxx@uwm.edu
For complaints or problems	Kristin Wiseley	xxx-xxx-xxx; xxx@uwm.edu
	IRB	xxx-xxx-xxxx / xxx@uwm.edu

Signatures

If you have had all your questions answered and would like to participate in this study, sign on the lines below. Remember, your participation is completely voluntary, and you're free to withdraw from the study at any time.

____

Name of Participant (print)

____ ____________________

Signature of Participant Date

Initial if you consent to have our interview voice recorded ______ ____________________

Date

____

Name of Researcher obtaining consent (print)

____ ____________________

Signature of Researcher obtaining consent Date

Appendix C

Interview Protocol Questions

The following questions were asked during the interviews:

Focused life history

Parent:

Race

Level of Education

Social Class

Child's name

Gender

Age

A. How did you find out your child had a significant disability?

- a. Who was involved?
- b. Where did you find out?
- c. When did it happen?
- d. What were you told?
- e. How did you feel?
- f. Who or what helped?
- g. Who or what made it challenging?
- h. What, if anything, would you change?
- i. What was surprising to you?

B. At each stage/transition: (Diagnosis, Birth-3, Home-to-School (Early Childhood), EC to Elementary, Elementary to Middle, Middle to High School, High School to Post-School)

  a. What did education look like for your child?
      i. Placement
      ii. Services
      iii. Staffing
  b. What did people do that met your expectations?
  c. What didn't meet your expectations?
  d. How were decisions made in regards to placement and programming?
  e. What surprised you at this stage/transition?
  f. What did you foresee for your child's future at this stage?
  g. Anything else?

C. What has been your experience with IEP meetings?

  a. Describe meetings with educational professionals and programs regarding your child's placement and programming (opportunities to learn)?
  b. Based off of Brookfield's Classroom Critical Incident Questionnaire (n.d.):
      i. When were you most engaged in the process?
      ii. When were you the most distanced in the process?
      iii. What action or something that someone did was most helpful?
      iv. What did someone do that really puzzled or confused you?
      v. What about the whole process surprised you?

Appendix D

LifeGrid

	Diagnosis	Birth-to-3	B-3 to EC	Early Childhood to Elem	Elem to Middle	Middle to HS	HS to post-school	IEP Process
Who was involved?								
Where did this occur?								
When did it happen?								
What happened?								
How did you feel?								
Who or what helped?								
What made it challenging?								
What, if anything, would you change?								
How were decisions made?								
What surprised you?								
What did you foresee for child's future?								
Brookfield 5 based IEP process questions								

CURRICULUM VITAE

Kristin Sara Wiseley, PhD
Department: Special Education

DEGREES

DEGREE	DISCIPLINE	INSTITUTION	YEAR
Doctor of Philosophy	Urban Education, Special Education	University of Wisconsin, Milwaukee	2020
Autism Studies Certificate	Autism Spectrum Disorders	University of Wisconsin, Milwaukee	2013
Master of Science	Early Childhood Special Education	University of Wisconsin, Milwaukee	2011
Teaching Certification	Early Childhood Special Education	University of Wisconsin, Milwaukee	2009
Teaching Certification	Cross-Categorical Special Education, MCEA	Cooperative Educational Service Agency (CESA)-1	2007
Bachelor of Science	Human Development and Family Studies	University of Wisconsin, Madison	2005

EXPERIENCE

RANK/POSITION	DEPARTMENT/DIVISION	INSTITUTION/ COMPANY	PERIOD
Assistant Professor of Special Education	School of Education/Special Education	Western Illinois University	Present
Adjunct Instructor	School of Education/Special Education	Western Illinois University	2020
Program Coordinator/Early Childhood Special Education	Department of Teaching and Learning/Exceptional Education	University of Wisconsin-Milwaukee	2019-2020
Job Coach	Young Adult Job Coaching	Marilyn Services, LLC	2019-2020
Adjunct Instructor	Department of Teaching and Learning/Exceptional Education	University of Wisconsin-Milwaukee	2018
Research Assistant	Department of Teaching and Learning/Exceptional Education	University of Wisconsin-Milwaukee	2017-2018
Program Developer/Teacher Certification Programs	School of Professional Studies/Special Education	Alverno College	2017
Supervisor/Student Teachers and Field Students	Department of Teaching and Learning/Exceptional Education	University of Wisconsin-Milwaukee	2016-2018

Supervisor/Student Teachers and Field Student	School of Professional Studies/Special Education	Alverno College	2016-2020
Adjunct Instructor	School of Professional Studies/Special Education	Alverno College	2016-2020
Intermediate School Teacher	Cross-Categorial Special Education/Grades 4-8	Deer Creek Intermediate School/St. Francis School District	2013-2016
Elementary School Teacher	Cross-Categorial Special Education/Grades 1-4	County Line Elementary School/Germantown School District	2011-2013
Elementary School Teacher	Cross-Categorial Special Education/Grade 4	Amy Belle Elementary School/Germantown School District	2009-2011
Elementary School Teacher	Cross-Categorial Special Education/Grades 1-2	Grewenow Elementary School/Kenosha Unified School District	2008-2009
Early Childhood Special Education Teacher	Kindergarten/ Cross-Categorical	Curtis Strange Elementary School/Kenosha Unified School District	2007-2008
Early Childhood Special Education Teacher	Kindergarten/Cross-Categorical	Red Apple School/Racine Unified School District	2006-2007

HONORS/AWARDS

HONOR/AWARD	**ORGANIZATION**	**YEAR**
Pi Lambda Theta	National Honor Society for Educators (Beta Epsilon Chapter)	2018
Phi Upsilon Omicron	National Honor Society in Family and Consumer Sciences (Nu Chapter)	2003

TEACHING EXPERIENCE

SUBJECT *Undergraduate (U), Graduate (G) Other (O)*	**INSTITUTION**
Instructional Methods for 7-12 Learners with Disabilities (G)	Western Illinois University
edTPA Seminar (U/G)	University of Wisconsin-Milwaukee
Introduction to Learners with Disabilities (U)	Alverno College
Characteristics and Evaluation of Learners with Disabilities (U/G)	Alverno College
Adaptations and Modifications for Learners with Disabilities (G)	Alverno College

Language and Literacy Development in Learners with Disabilities (U/G)	Alverno College
Self-Contained Special Education Core Curriculum/Essential Elements (O)	Deer Creek Intermediate School
Special Education Resource (O)	County Line Elementary School
Special Education Resource (O)	Amy Belle Elementary School
Special Education Resource (O)	Grewenow Elementary School
Kindergarten Core Curriculum/Special Education (O)	Curtis Strange Elementary School
Kindergarten Core Curriculum/Special Education (O)	Red Apple Elementary School

RESEARCH

REFEREED PUBLICATIONS

Journals

Resch, K., **Rice, N.**, & Wiseley, K. (Under Review). Reading instruction for adolescents labeled learning disabled (LD). *Reading Research Quarterly*.

OUTREACH

PROJECT	PARTICIPANTS	PERIOD	SPONSORSHIP
Teaching Writing Strategies Training Sessions and In-Services	Secondary Special Education Teachers	2019-2020	US Department of Education
Teaching Reading Strategies Training Sessions and In-Services	Secondary Special Education Teachers	2019	US Department of Education

SERVICE

INSTITUTION	COMMITTEE-ACTIVITY	PERIOD
Alverno College	External Reviewer for Student Teacher Portfolios	2017-2018
Alverno College	School of Education-Literacy Advisory Council	2016-2017

MEMBERSHIPS

ORGANIZATION/COMPANY	PERIOD
American Educational Research Association (AERA)-member	2019-Present
Pi Lambda Theta-member	2018-Present
Council for Exceptional Children (CEC)-member	2017-Present
Phi Upsilon Omicron-member	2003-Present