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A GROUNDED CASE STUDY OF PARENTAL PERCEPTIONS SURROUNDING FORMALIZED SPECIAL EDUCATION PROCESSES

by

William Eric Strong

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

of

DOCTOR OF PHILOSOPHY

in

Education

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ABSTRACT

A Grounded Case Study of Parental Perceptions Surrounding Formalized

Special Education Processes

by

William Eric Strong, Doctor of Philosophy Utah State University, 2017

Major Professor: Steven P. Camicia, Ph.D.

Department: School of Teacher Education and Leadership

This dissertation is a qualitative, exploratory, grounded theory multiple case study using critical discourse analysis and selected critical disability theory methodology. I explore parental perceptions surrounding discourses stemming from formalized special education processes, federal requirements encountered by parents and their children with disabilities or suspected disabilities. These processes purportedly protect the rights of children with disabilities by helping them make academic gains through scaffolds that meet their individual needs. During this process, parents of children with disabilities become empowered or disempowered by discourses focused on eligibility for special education services and Individualized Education Plans. These discourses may serve to privilege, empower, disempower, alienate and marginalize, or unite and value. I critically examine and address instances of this discourse to support and empower parents concerning instances of negatively framed discourse and to assist administrators, professionals, and teachers reframe and improve information delivery.

I discuss grounded theory, *Critical Disability Theory*, *Power Theory*, disability models, parent perceptions literature, the special education process, and uncovered themes.

This study involves 15 survey participants and 14 remaining case-study participants who have or have had children with disabilities go through the special education process from five separate school systems within the Western U.S., recruited through district cooperation or *snowball* methodology. I utilize a survey covering perceptions and attitudes about formalized special education processes along with openended, semi-structured interviews for case-study analysis. I provide survey analysis related to uncovered codes and themes. Participants discussed inequities and inequalities such as a perceived lack of power and voice during these meetings. They referred to lost dignity for themselves and their children with disabilities and high levels of frustration due to poor communication and follow-through. Participants perceived successful interactions from the persistent effort, advocacy, and self-education on special education law, procedure, and the disabilities of their children. I provide participant summary perceptions and desires regarding the special education process. I present two models of special education discourse derived from grounded theory and discuss my results regarding models of disability, a school-equity-improvement model, an ethical framework, and I argue for a call to action to begin the groundwork for positive, lasting change.

PUBLIC ABSTRACT

A Grounded Case Study of Parental Perceptions Surrounding Formalized

Special Education Processes

William Eric Strong

In this dissertation, I explore, through qualitative means, the perceptions of parents related to discourse (what is said and not said) within formalized and required processes of special education. These processes are federal requirements that parents of children with disabilities or suspected disabilities encounter as their children progress through the school system. The processes purportedly protect the rights of children with disabilities. The goal of the process is to help children with disabilities make academic gains by providing scaffolds that meet their individual needs.

During this process, parents of children with disabilities become empowered or disempowered by discourses focused on eligibility for special education services and Individualized Education Plans. These discourses may serve to privilege, empower, disempower, alienate and marginalize, or unite and value. I critically examine instances of this discourse to support and empower parents concerning instances of negatively framed discourse and to assist administrators, professionals, and teachers. My goal is to help these individuals understand how parents perceive the discourse within this framework. I aim to lessen instances of alienation, marginalization, and power inequities that parents repeatedly encounter through education.

This study involves 15 survey participants and 14 remaining case-study

participants who have or have had children with disabilities go through the special education process from five separate school systems within the Western U.S. I utilize a survey covering perceptions and attitudes about formalized special education processes along with open-ended, semi-structured interviews for case-study analysis. Participants discussed inequities and inequalities such as a perceived lack of power and voice. They referred to lost dignity for themselves and their children with disabilities and high levels of frustration due to poor communication and follow-through. Participants perceived successful interactions from persistent effort, advocacy, and self-education on special education law, procedure, and the disabilities of their children. I provide participant summary perceptions and desires regarding the special education process. I present two models of special education discourse derived from grounded theory and discuss my results regarding models of disability, a school-equity-improvement model, an ethical framework, and I argue for a call to action to begin the groundwork for positive, lasting change.

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I would like to begin first with a heartfelt thank you to a committee member, Dr. Susan Turner. In 2008, while taking a Supervision in the Public Schools course here at Utah State University, an effort to move beyond failure, disappointment, and unexpected life events—an All-But-Dissertation Ph.D. attempt from the University of Washington—Dr. Turner called me aside after class and candidly asked why I was not in a Ph.D. program. Over the next couple of years, as I pursed my administrative credential, she continued to nudge and encourage this kernel thought and supported me while this idea flowered into an application for doctoral study at Utah State University through the Department of Curriculum and Instruction. I am forever grateful for her letter of recommendation and advocacy. In multiple meetings, Dr. Turner provided the department administration reassurance regarding my writing and thinking skills and advocated for maximization of past doctoral level credits. Without her gentle push at that time, I am certain this dissertation would not have seen the light of day.

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and dedication to my topic and interests, as well as his kindness, nurturing, availability, and suggestions through all stages of this investigation.

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William Eric Strong

DEDICATION

I dedicate this dissertation to my children and stepchildren, Tori Strong, Will Strong, Garrett Bates, and Alex Ryvers. Tori and Alex, I am proud of the young women you have become. I know that both of you will find your way; although you both too often hide your inner strengths, I see them clearly, and they are beautiful. Take the effort to unleash those strengths—let them shine. Be bold. Be brave. As you do this, happiness will surround you. Importantly, thank you for motivating me (and Elizabeth) on our academic journeys. Will and Garrett, I am proud of the young men you have become—continue to pursue your passions. Follow your heart. Remember, money and success do not typically equate with happiness. As an example, look no further than Elizabeth and me. Importantly, thank you for your motivation, encouragement, and support throughout this tortuous degree.

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CHAPTER I

INTRODUCTION, PROBLEM, AND RESEARCH QUESTIONS

Introduction

"I felt when I left most of those meetings that I didn't have a clue what I was doing as a parent" (Evelyn, personal communication, April 7, 2017).^{1, 2}

I hear Evelyn, a young, married mom of three children, say these words. We are about twenty minutes into my first interview for this dissertation project. I feel my heart sink. "Not again," I think. "These stories just break my heart." I smile, couch these thoughts, and let Evelyn continue her train of thought. Evelyn is not my first parent to say these words. As she does, she reveals an unspoken power differential between school team members and the parent and resulting loss in self-confidence and dignity. My inner voice also knows she will not be the last.

As a speech-language pathologist for 27 years, I hear parents express this sentiment from time to time, especially as I begin to treat their child and a level of rapport and trust develops. This openness from parents occurs typically after several interactions. In my view, parents begin to speak about these perceptions and concerns because they see me honor my "responsibility to hold paramount the welfare of persons [–the parent

¹ All participant names are pseudonyms, as are names of family members—including the children with disabilities. I also refer to professionals by their title, schools by their level of service (e.g., middle school), and locations by their general geographic area (e.g., suburban community in the Southwestern U.S.) to respect the anonymity of those participating and the site that provided cooperation.

² All participant 'personal communication' referenced in this dissertation are *audio-recorded interviews*, recorded via a Sony IC multi-directional digital recorder (MN: ICD-SX712) for the 2013 participant interviews and a Surface Pro3 with Windows 10 and Voice Recorder application for the 2017 participant interviews.

and child—I] serve professionally" (American Speech-Language-Hearing Association, 2016, p. 4). This responsibility includes the care and effort to provide all clinical services competently. This responsibility also means using "resources, including referral and/or interprofessional collaboration when appropriate, to ensure that quality service is provided" and not discriminating "in the delivery of professional services" (American Speech-Language-Hearing Association, 2016, p. 4). Parents see the words I live by through my actions with their child, with them, and with other team members.

In my pilot dissertation project, four parent participants express the same sentiment as Evelyn. They too report a loss of power, a loss of dignity, a lack of empathy from the members within the special education process. Moreover, I too—a professional in the field of specialized instruction and related services—had held the same feelings of doubt and inadequacy when one of my children began her journey into the realm of special education services. I remember thinking, "I know what I am talking about. I see the behavior at home; I see it when I visit her class. Why can't you acknowledge these issues? They are not typical. I am not overreacting." At the time, the problems my daughter demonstrated at home, in school, and at her after-school daycare were, in my view, clear and genuine signs of significant underlying issues; the district she was attending at the time thought otherwise. It took considerable time, effort, and resources both external and financial—to shed light on her issues and to get cooperation from her school and district. When my daughter turned 22, I finally relinquished the grip of that era and its many disdainful memories through a shredding celebration; from a bookcase, I took three three-inch binders full of legal documents. These binders, organized by year and filled with depositions, hearings, testimony, independent educational evaluations,

formal letters to the district, and research on similar court proceedings, were a nearly 4-year chronology of stress—the sequelae of many sleepless nights. Within the text of these documents was a steadfast discourse of advocacy and intent for getting my daughter specialized instruction services that I believed she so obviously needed. Now a month after interviewing Evelyn, I meet Janet, a mother of triplets. As we talk, she expresses the deep frustration about the special education process that I felt when working toward a resolution for my daughter through the court system. Janet tells me during the interview, "One thing is [I wish] it wouldn't take so damn long (Janet, personal communication, May 22, 2017).

A shorter length of time between start and finish is *Janet*'s wish for the special education process; it reflects the frustration and 2½-year period it took for her daughter to get specialized instruction services for a reading disability. I hear this frustration on the second day of summer vacation; the weather and temperature are perfect. I have met Janet at her home along with an enormous Great Dane named Ziggy, and her three rambunctious children who were "bored with nothing to do." *Janet* and I joke because in her backyard is a pool, trampoline, and a small playground. We also joke because Ziggy decides it is time for an ear rub and I must give it; Ziggy spends most of the interview with his head in my lap, nudging my hand whenever I stop the head massage. At the same time, her children beg for attention; they run back and forth through the dining room where we have chosen to sit. The children, opening and closing a sliding glass door to go in and out of the house, giggle and scream as they chase and play. Through these interruptions, Janet describes the need for accountability, the need for follow-through, and her lack of trust with the special education process due to the teams' inability to

identify her daughter's reading problem after 2.5 years:

At the meeting, everything sounded great, and I left the meeting feeling wonderful. Then in reality and as we watched, those feelings have gone away because they are not being met. It was like; we wrote this down to make sure that we crossed all our t's and dotted all our i's and then, we are going to do what we want. So, I was a trauma critical care nurse for years, I've worked with surgeons that I would not trust to touch me, my dog, my tuna, nothing. Not like, a dead mouse in the yard. [Laughter].

And then I've worked with others that if they had two good cells, they could fix the problem. I mean, and so, I've seen an array of differences among professionals. So, just because you have initials, a certain education, doesn't make me go, oh, you must know everything. So, I automatically have that, okay, let's hear your rationale. I'm open to it, but I'm not just going to accept it because you're the, whatever. So, and I said, I will fight. This isn't the last of it. I said, rest assured, you're not going to get rid of me. (Janet, personal communication, May 22, 2017)

Two days after interviewing Janet, a meet Carrie, a mom with a son, Max, who has just finished 11th grade. Max struggles with language processing, comprehension, reading, oral and written expression. Carrie is talking about the evaluation review meeting. Professionals hold his meeting to make educational decisions. At the meeting, professionals discuss testing results and interpret them for the parent's benefit.

Carrie tells me, "So, I never really got her interpretation of what she thought was going on" (Carrie, personal communication, May 24, 2017).

Carrie expresses frustration in her text and through her tone when she describes what happened at her child's evaluation review meeting. The evaluator or diagnostician for her child—the professional who interprets and reports testing—was absent during this meeting and did not preview the results with Carrie or follow-up. I bit my lip on this news trying not to reveal my discomfort. The law is clear: the diagnostician must be present to interpret and answer questions before eligibility considerations (Individuals

with Disabilities Education Act [IDEA], 2007d). Team members can hold the evaluation review in conjunction with the IEP meeting or separately. Considering Carrie's text, I reflect on times professionals have been absent in meetings when I have been a team member. I also reflect on I how I handle my absences when they occur. I might ask another professional to sit in and interpret. I might call the parent before the meeting and email them my report, discussing results over the phone. Alternatively, if those methods are not successful, I postpone the meeting until my health improves or I am available so that I can personally convey results, interpret the findings, and be available to ask and answer their questions. Later, Carrie expresses the frustration of her husband. She says:

So, I asked my husband before I came here this morning if he had anything to share with you and if he wanted to come. And he just said, "The whole process is a waste of time. We can say whatever we want to say, but they have a preconceived idea of what they are going to do. And it doesn't matter what you say because that's what's going to be done. And it's like you're not even in the room." (Carrie, personal communication, May 24, 2017)

Carrie sums up her experience with the special education process: "I think that pretty much sums it up. Frustration, frustration, frustration. Parent's crazy, and the kid's fine.

That's the impression I get from them." (Carrie, personal communication, May 24, 2017).

Introductory Statement

This research is a qualitative, exploratory, grounded theory case study using critical discourse analysis (CDA) and select Critical Disability Theory (CDT) methodology and concepts to interpret perceptions held by parents whose children with disabilities are currently experiencing or who have experienced the special education process. I have two primary questions: What is the meaning of special education from the perspective of parents who have or have had children enrolled in special education, and

what is the experience of parents who participate or have participated in the special education process? I ask these specific questions because my broader goal is to understand the perceptions of parents who have children with disabilities that arise from a set of entwined social relations embedded in systemic complexities and constraints.

These complex constraints are the formalized processes and mores that define the process of gaining access to special education.

Positionality

I come to this research as a married, middle-aged, middle class, White, male, Ph.D. student. I am a life-long learner and have been a Speech-Language Pathologist for 27 years (17 years in the school system) and have previously held special-education administrative duties, as well; in other words, I have encountered thousands of children with disabilities and their parents. Also, I am the father of two children with disabilities. As such, I have been a parent and professional at school-based Individual Education Plan (IEP) and evaluation review meetings. Moreover, I have disabilities; I struggle with stuttering and auditory processing challenges. My spouse, who is a speech-language pathologist and Educational-Doctoral Candidate, has a reading disability and the ongoing sequelae of a severe concussion.

Positionality Guidepost

Having been a parent and professional at IEP meetings, I have had the opportunity to both deliver and receive difficult news. As such, I empathize and understand the parent perspective; this has changed the way I position my body, tone, attitude, words, as well as quantity and quality of information to meet parent needs. As stated by Mohandas

(Mahatma) Gandhi (Greenburg, 2015) "Three quarters of the miseries and misunderstandings in the world would finish if people were to put on the shoes of their adversaries and understood their points of view" (slide 3 of 8).

On the one hand, this positionality may provide a more objective/balanced analysis of perceptions reported by parents; I understand both the reasoning behind and need for a formalized process, as well as the hopes and dreams a parent has for their son or daughter. On the other hand, it may bias/slant my analysis toward the side of the parent as I have seen and experienced poor informational delivery and its unintended consequences. For example, I have witnessed professionals who present test results without acknowledging a parent's cognitive overload following difficult news about their children, such as a diagnosis of autism, cognitive impairment, or emotional disturbance. In many of these instances, educational jargon, a deficit-based framing of the child's challenges, and an unexpected diagnosis have been the rule.

Pilot Study

In consideration of my positionality and the guidepost to my positionality, during the fall semester of 2013, I embarked on a pilot study—specifically, an exploratory, critical ethnography case study; it was a required project for a qualitative research course. The study involved six parents who had children with disabilities from a small, rural town within the intermountain region and a small city in a second state within the intermountain region. I chose this topic because I had become interested in applying the difficulties and challenges I was witnessing in my professional career to the educational theory I was encountering in my doctoral program. As such, I began to reflect on the

concepts of *hegemony* and *discourse*. These concepts will be defined and discussed fully in later sections of this chapter, however, for clarity, I begin to introduce them here.

Stoddart (2007), referring to Gramsci (1992), described *hegemony* as a concept that lies between "coercion and consent as alternative mechanisms of social power" (p. 137). Stoddart explained:

Coercion refers to the State's capacity for violence, which it can use against those who refuse to participate in capitalist relations of production. By contrast, hegemonic power works to convince individuals and social classes to subscribe to the social values and norms of an inherently exploitative system. It is a form of social power that relies on voluntarism and participation, rather than the threat of punishment for disobedience. Hegemony appears as the "common sense" that guides our everyday, mundane understanding of the world. It is a view of the world that is "inherited from the past and uncritically absorbed" and which tends to reproduce a sort of social homeostasis, or "moral and political passivity" (Gramsci 1971, p. 201)

Stoddart (2007) also described *discourse* from the standpoint of Foucault (1978) by noting that "discourses are systems of thought, or knowledge claims, which assume an existence independent of a particular speaker" (p. 203). Stoddart explained further that "discourse is an important object of social analysis, in and of itself" (p. 206).

When I embarked on my pilot study, my research questions were: (a) as viewed by parents who have experienced critical moments of the special education framework what were instances of hegemonic discourse, if any occurred? And (b), as viewed by parents who have experienced critical moments of the special education framework at what point in the process do instances of hegemonic discourse occur and by whom, if any occurred?

While the data from this investigation might not be transferable to similar contexts as saturation of themes and codes was not achieved, the research, in my view,

was of value. Following the project, I understood the methods involved in conducting qualitative research as well as a rich understanding of the following themes: power imbalance, empowerment, inequality, inequity, equality, equity, dominance, repression, hegemony, victimization, voice, and lack of voice from the perspective of parents. Within these pilot data, there is a notable disparity toward responses negative of or highly critical of the special education process (131 total negative statements), indicating that the method of delivering information and enrolling children into special education remains insufficient or inadequate. The obtained data are not unlike data found in the literature in which reports of ongoing difficulties within special education are detailed. From the total data set, six hours of open-ended interview questions and the resultant responses, I coded 22 parent responses as *Power Imbalance*, 8 responses as *inequality*, and 15 as *inequity*. There were also 3 instances of dominance, 22 instances of repression, 18 instances of hegemony, 28 instances of victimization, and 15 instances of having a lack of voice. In contrast, of the 82 total positive comments, there were 36 parent comments coded as empowerment, 13 responses coded as equality, 20 responses coded as equity, and 13 responses coded as having a voice (see Appendix 1, Pilot Study Coding Data). As such, 63% of the parent responses in this data set were unfavorable, and 37% of the parent responses were favorable toward the special education process. Interestingly, all the pilotstudy participants expressed the appreciation of a chance to be heard.

For this dissertation project, I introduce in the following paragraphs two examples of one theme, *power imbalance*, and one example of a second theme, *empowerment*, uncovered in the pilot study:

Power imbalance refers to one group or individual, typically those in authority or

dominant racial class, holding their position as a means of control over an individual or group (Foucault, 2003). Concerning schools and special education programs, those with less power are typically the parent, and by extension, the child with disabilities (Tozer, Senese, & Violas, 2009). I explain these school-related issues in the Historical and Contextual Framework section below. During the pilot study, I described to parents the issue of 'power' as how much 'voice, say, or authority' the parent feels she or he had during moments of the special education process. One participant of that pilot study, Denise, reveals instances of power imbalance when discussing how long it took for her child to receive special education services "of about a year" (Denise, personal communication, March 11, 2013):

From the first time that we started observations when I first contacted her, the first observation was done within a day or two. So, our first contact started then, we did the testing which took, maybe, a couple of weeks, by the time they finished testing and I received the results from that. The testing did show a reading disability, very early on at kindergarten level. But, because he was so young, there's ...there's no diagnosis that they gave or pursued. So, that's where difficulties started. I had to go to a doctor, and the doctor said the school would do it and the school said the doctor's do it. Um, I ended up taking him to the university for add...additional testing. Um, but they gave the same tests that he had already received at the school, so I paid a lot of money for no information. So, that was a frustrating process. It wasn't until he was in first grade that they did a few more tests and he was finally able to get a diagnosis about half-way through the year, so from the time we started to the time he was qualified for an IEP was about a year. (Denise, personal communication, March 11, 2013).

Denise's response demonstrates how those in Authority held their power over her and her child. Denise states that a school evaluation had uncovered reading challenges, but the school refused the child a Free Appropriate Public Education (FAPE; Every Student succeeds Act [ESSA], 2015; IDEA, 2007e). Although the student qualified based on test scores, the district did not provide the student with the specialized instruction

following the test results. In fact, Denise, following this interaction tries other avenues; she sees her child's pediatrician and a university for testing to no avail. Demographically speaking, Denise is low socioeconomic status (SES); her children receive "free or reduced lunch" at school as well as a free breakfast. This further increases the uncovered power imbalance.

As another example of power imbalance from my pilot study, Grace, who discusses the evaluation review as it related to her daughter, Carlie, reveals a power differential due to her lack of knowledge:

I didn't feel like I had a lot of voice. If I had known, I think I'd...I felt like I was just watching. I should have been more vocal. I think I should have.... I would have liked to have been more informed about the importance of the meeting. My impression was that they were just taking a benchmark, evaluating her. I didn't realize that it was this competition and in retrospect, I should have.... I wish I had been more informed about the significance of this meeting—that it was going to determine how many services she got for the next few years. (Grace, personal communication, June 14, 2013).

Grace is a professional with multiple professional degrees and upper SES status.

Despite her education and community stature, Grace reveals instances of a power imbalance in her narrative that had occurred many years ago. The pain from that meeting, however, was ever present in her dialogue, her trembling voice, and tears that streamed down her face as my interview with her took place.

A different theme that emerged from my pilot data is empowerment. Instead of disempowering Maggie, the discourse she experiences empowers her:

Well, I felt like I could say my opinion. I felt like I could express myself and ask questions. The questions I asked, I felt were answered appropriately. They weren't responding in a demeaning way or whatever because I didn't know. You know, this is a whole world of speech pathology that I am not acquainted with, and they were very professional and would professionally answer my questions. So, I didn't feel like I couldn't speak, and I felt like my questions were answered

appropriately (Maggie, personal communication, June 19, 2013).

Problem Statement

In the following sections, I present key terminology and discuss the problem that brought this research forward. I follow this with a historical and contextual account of disability education. Last, I summarize the problem.

Key Terminology

First, I define the concept of discourse, then a method known as critical discourse analysis. I follow this with the concept of hegemony and introduce CDT. Understanding these terms is necessary for unpacking the discussion, understanding the results, and following the interpretation. I present these terms below.

Discourse. Of interest to me is the *discourse* parents experience during critical moments of the special education process. S. Hall (2001) discussed discourse as he referenced Foucault's explanation. S. Hall wrote that discourse:

Defines and produces the objects of our knowledge. It governs the way that a topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others. Just as a discourse 'rules in' certain ways of talking about a topic, defining an acceptable and intelligible way to talk, write, or conduct oneself, so also, by definition, it 'rules out', limits and restricts other ways of talking, of conducting ourselves in relation to the topic or constructing knowledge about it. (p. 72)

Discourses, then, "function to maintain what does and doesn't get said and known" (Camicia, December 6, 2016, personal communication). As such, the purpose of my research is to reveal the discourses these parents experience and to explore their functions within the context of the formalized special education process. How do they function? Do the discourses function as a tool to empower or disempower and who does this discourse

privilege? Likewise, do the discourses these parents experience function to alienate and marginalize or unite and value?

Critical discourse analysis. To analyze discourse, then, one methodology is CDA. In CDA, language is a social practice (Fairclough & Wodak, 1997) and the context of language use is crucial. To enrich the above definition of discourse, Fairclough and Wodak wrote for those who practice CDA, *discourse*—language use in speech and writing—is:

...a form of "social practice." Describing discourse as social practice implies a dialectical relationship between a particular discursive event and the situation(s), institution(s) and social structure(s), which frame it: The discursive event is shaped by them, but it also shapes them. That is, discourse is socially constitutive as well as socially conditioned—it constitutes situations, objects of knowledge, and the social identities of and relationships between people and groups of people. It is constitutive both in the sense that it helps to sustain and reproduce the social status quo and in the sense that it contributes to transforming it. Since discourse is so socially consequential, it gives rise to important issues of power. Discursive practices may have major ideological effects—that is, they can help produce and reproduce unequal power relations between (for instance) social classes, women and men, and ethnic/cultural majorities and minorities through the ways in which they represent things and position people. (p. 258)

Thus, by implementing CDA, discourses are viewed as a "relatively stable uses of language serving the organization and structuring social life" (Wodak & Meyer, 2009, p. 6). Likewise, in referring to Foucault (1995/1975) and Giddens (1984), Wodak and Meyer articulated that in CDA, power is seen "as a systemic and constitutive element/ characteristic of society (e.g., from very different angles)" (p. 9).

As discourses function to maintain what does and doesn't get said and known, by practicing CDA, one is: "...fundamentally interested in analyzing opaque as well as transparent structural relationships of dominance, discrimination, power and control as manifested in language" (Wodak & Meyer, 2009, p. 10). In other words, according to

Wodak and Meyer, the goal of those who practice CDA aim "to investigate critically social inequality as it is expressed, constituted, legitimized, and so on, by language use (or in discourse)" (p. 10).

Fairclough and Wodak (1997, pp. 271-280) summarized the tenets of CDA: first, CDA addresses social problems; second, power relations are discursive; third, discourse constitutes society and culture; fourth, discourse does ideological work; fifth, discourse is historical; sixth, the link between text and society is mediated; seventh, discourse analysis is interpretive and explanatory; and eighth, discourse is a form of social action.

Hegemony. Of additional importance, here, and embedded within the text of Fairclough and Wodak's (1997) definition of discourse is the concept of hegemony: the preponderant influence of authority over others. In discussing Gramsci's (1978) concept of hegemony, Strinati (2004) writes that hegemony functions to help:

...Dominant groups in society, including fundamentally but not exclusively the ruling class, maintain their dominance by securing the 'spontaneous consent' of subordinate groups, including the working class, through the negotiated construction of a political and ideological consensus which incorporates both dominant and dominated groups. (p. 153)

Crucial to hegemony is how it "acts to 'saturate' our very consciousness, so that the educational, economic, and social world we see and interact with, and the commonsense interpretations we put on it, becomes the world *tout court*, the only world" (Apple, 2013, p. 23).

Apple (1997) further emphasized that hegemony "refers to an organized assemblage of meanings and practices, the central, effective and dominant systems of meanings, values actions which are lived" (p. 4). It is here that "certain meanings and practices are chosen for emphasis, certain other meanings and practices are neglected and

excluded" (p. 5). Apple's point is that hegemony needs to be understood on a level that is different from "mere opinion or manipulation" (p. 4). Stoddart (2007) built on this idea. He stated that:

...hegemonic power works to convince individuals and social classes to subscribe to the social values and norms of an inherently exploitive, treat of punishment for disobedience. (p. 201)

In summary, hegemony "involves an all-encompassing system where "common sense" remains unexamined and inequitable systems go unquestioned" (*Camicia*, Dec. 6, 2016, personal communication). The world, in other words, is viewed whereby it is "inhered from the past and uncritically absorbed" (Gramsci, 1971, p. 333). This view reproduces a "moral and political passivity" (Gramsci, 1971, p. 333).

Critical disability theory. Briefly, CDT is a theory that finds disability to be a social construct, rather than the "inevitable consequence of impairment" (Hosking, 2008, p.7). CDT takes its shape from the impact of pervasive discrimination, prejudice, assumptions, institutions, and structures that place persons with disabilities at a disadvantage (Devlin & Pothier, 2006). This concept will be explored thoroughly in Chapter II, Theoretical Frameworks, and Literature Review.

Terminology Summary

In thinking, then, about these concepts—hegemony and discourse—I intend to uncover potential "taken-for-granted assumptions" (Camicia, December 6, 2016, personal communication) that may exist within the special education process that function to create and maintain social inequalities. To accomplish this, I utilize the perceptions of parents who have experienced this process. This process is known as CDA. One potential

explanation for findings related to disability is that of CDT. However, in this investigation, my findings build the theory from the ground.

Historical and Contextual Framework of Disability Education

Considering my pilot study, in this section, I present the historical and cultural context of special education—one that has often privileged a scientific, medical, and deficit-based view of educational challenges. I present these contexts so that the reader can better understand the discourse that parents may experience in meetings focused on their children with disabilities. Following this discussion, I consider ways in which CDT might inform our understanding of the hidden power relations within the team meeting context.

Historical context. To fully appreciate the existing inequities, inequalities, and hegemony that parents and their children with disabilities experience, a historical review is necessary. It is necessary to understand first why public law 94-142, also known as the Education for All Handicapped Children Act (20 U.S.C.A 1400(b), 1975) became federal law. It is also necessary to understand why reauthorization and modification of that original law continue to be necessary.

Separate but not equal. Historically, the educational experience of children with disabilities is not unlike that of African American children taught in segregated classrooms before 1950; in discussing children with disabilities, Chinn (2004) wrote:

They were either excluded from public education or at best segregated in special-education classrooms. Availability of services was typically determined by the nature of the disability and sometimes the degree of disability. State schools throughout the country institutionalized many of the children with severe disabilities, such as intellectual disability. Often, these institutions were

deliberately located away from the population centers and away from nondisabled individuals. State schools for the blind and schools for the deaf were also established, perpetuating a disposition toward segregated education for those with disabilities. (p. 9)

Fortunately, for African American children—and the seeds for change for children with disabilities—change began in the summer of 1950 when thirteen African American families in Topeka, Kansas took their children to neighborhood schools to enroll them for the upcoming school year. Due to their skin color, they were could enter the schools (Russo, 2004). The district demanded the children travel some distance from their homes and attend one of four schools for African Americans in the city. On behalf of their twenty children and against the Topeka Board of Education, these parents filed suit in February 1951. A minister, Oliver Brown, was listed first on the lawsuit and, as such, has the distinction of having the case named after him. Even though the U.S. District Court ruled against the plaintiffs, they accepted the record segregation had adversely affected African American children. Later, these findings were used by the U.S. Supreme Court to support its 1954 opinion, Brown v Board of Education. This decision brought about the end of segregation (Brown v Board of Education, 1954). This court case also determined that "The 'separate but equal' doctrine adopted in *Plessy v* Ferguson, [italics added] 163 U.S. 537 (1896) has no place in public education" (Chinn, 2004).

First cases. Likewise, before the arrival of special education law in 1975, some school districts throughout the country continued to deny an appropriate public education to children with disabilities in a similar fashion to the resistance to racial integration at the time (Chinn, 2004). This denial of education continued for children with disabilities

despite state-sponsored legislative measures, numerous lawsuits, and the "reasoned treatment of the disability question by the courts in 'PARC' and 'Mills'" (Alexander & Alexander, 2009, p. 568), two separate special-education law cases that are of equal importance.

Pennsylvania Association for Retarded Children [PARC] v. Commonwealth of Pennsylvania (1972). The first case concerns the PARC. In 1971, this agency sued the Commonwealth of Pennsylvania. At the time, a state law within Pennsylvania allowed public schools to deny education to children who were not 5-years of age, mentally. This law, utilized consistently by districts within the state of Pennsylvania, denied education to students considered as burdensome. This case was the first challenge to laws that prohibited students with intellectual disabilities attend school with their peers (Chinn, 2004). Before this case, many states had legislation in place to prevent children with intellectual disabilities from receiving a free public education.

PARC alleged 14th amendment violations of due process by the state (Chinn, 2004). The plaintiffs argued that all children can benefit from an educational program and that the absence of this education leads to consequences that are negative developmentally. With education, these children, however, could achieve some degree of self-sufficiency. PARC also took a stance on the benefits of early education, arguing that the State, in sum, denied children their rights to due process and education through the education laws (Chinn, 2004).

Based on the evidence, in early 1972, the case was settled. A U.S. District Court Judge gave a consent decree deeming the former laws unconstitutional and tasked the State with providing free public education to all children between the ages of 6 and 21

years (Alexander & Alexander, 2009). Additionally, Alexander and Alexander noted that the State had to provide training and education for all "exceptional" children at a level commensurate with that provided to peers. In other words, Pennsylvania could no longer deny a child with a disability access to a free and appropriate public education.

Mills v. Board of Education of the District of Columbia (1972). While the PARC case never rose beyond the district court level, it encouraged others to act. After the PARC decision, the U.S. District Court of the District of Columbia presided over another case brought forth by the family and friends of Peter Mills, as well as, seven other children against the District of Columbia. Peter, a 12-year-old student, had behavioral issues. The school district, asserting expense, excluded Peter from attending. The district argued that it would cost millions of dollars to educate students like Peter and was, therefore, an undue burden (Chinn, 2004).

In the district court decision, the judge stated that children who are eligible for a publicly supported education could not be denied such education without an equal alternative tailored to the child's needs. The judge noted that the district's practice of excluding children with disabilities from education was unlawful. Moreover, the judge ordered the district to first, provide accessible, free, and suitable education for all children regardless of disability or impairment. Next, the district could no longer suspend a child for more than two days without a hearing. Last, the judge ordered the district to provide all parties in the suit with publicly supported educational programs tailored to their needs (Alexander & Alexander, 2009).

The Education for All Handicapped Children's Act (PL 94-142). Dozens of lawsuits followed (46 total in 28 states). Those filing the lawsuits challenged unfair

statutes and practices that were prevented children with disabilities from receiving a public education (Chinn, 2004). This trend led to the *Education for All Handicapped Children Act* (EAHCA; 1975). For many children denied the opportunity of a free, appropriate, public education, this law made that concept reality.

Resulting from this resistance, a "near-dormant humanitarian impulse of the public...awakened by these legal actions...spilled over to...legislative bodies," including Congress, with both chambers introducing legislation to eliminate discrimination of individuals with disabilities in both the work-and public-educational environments (Alexander & Alexander, 2009, p.568). Concerning education, the EAHCA (PL 94-142) of 1975 mandated the provision, disabilities (Alexander & Alexander, 2009, p. 568) because, as noted by Congress in 1975:

(1) there are more than eight million handicapped children in the U.S. today; (2) the special educational needs of such children are not being fully met; (3) more than half of the handicapped children in the U.S. do not receive appropriate educational services which would enable them to have full equality of opportunity; (4) one million of the handicapped children in the U.S. are excluded entirely from the public school system and will not go through the educational process with their peers; (5) there are many handicapped children throughout the U.S. participating in regular school programs whose handicaps prevent them from having a successful educational experience because their handicaps are undetected; (6) because of the lack of adequate services within the public school system, families are often forced to find services outside the public school system, often at great distance from their residence and at their own expense; (7) developments in the training of teachers and in diagnostic and instructional procedures and methods have advanced to the point that, given appropriate funding, State, and local educational agencies can and will provide effective special education and related services to meet the needs of handicapped children; (8) State and local educational agencies have a responsibility to provide education for all handicapped children, but present financial resources are inadequate to meet the special educational needs of handicapped children; and (9) it is in the national interest that the Federal Government assist State and local efforts to provide programs to meet the educational needs of handicapped children in order to assure equal protection of the law. (EAHCA, 1975)

These facts brought forth law meant to ensure that children with disabilities have educational rights. These rights include FAPE, an individualized education program (IEP), special education services, related services, due process procedures, and a least restrictive environment (LRE) in which to learn (EAHCA, 1975).

Reauthorization. Since its inception, this law has been amended, reauthorized, renamed, and reframed numerous times. Its original intent, however, has remained the same: to provide individuals with disabilities access to public education. After being referred to as EAHCA (1975), the law was eventually renamed IDEA (1997). This law, reauthorized in 2004 (Individuals with Disabilities Education Act, 2004), was subsequently placed under the umbrella of the No Child Left Behind Act (NCLB; 2001, 2004). In its latest form, NCLB (2004) has been replaced by ESSA (2015) and the Elementary and Secondary Education Act of 1965 has been reauthorized to ensure opportunity for all American Students. As of the 2011-12 school year, 6.4 million children and youth—12.9% of the general student population ages 3 to 21—received special education services (U.S. Department of Education, National Center for Education Statistics, 2015). In its newest form, the ESSA purports to advance equity by "upholding critical protections for America's disadvantaged and high-need students" (ESSA, 2015).

Ongoing challenges. Despite the passage of federal laws that protect the education of students with disabilities, school leaders continue to struggle with meeting both the intent and the spirit of the law (Turnbull & Ciley, 1999). For example, studies demonstrate a lack of parental involvement in the IEP process; this includes a lack of participation in developing objectives, shaping educational programs, and deciding on assessment procedures (Lynch & Stein, 1982)—all critical component of the democratic

IEP ideal. Goldstein, Strickland, Turnbull, and Curry (1980) and Yoshida, Fenton, Kaufman, and Maxwell (1978) found that even though parents may be present at the IEP meeting, most had "no involvement in developing objectives, interventions, or methods of evaluation" (p. 531). Likewise, parents of children with disabilities, ages zero to three, report that "Independent Family Service Plans were not developed jointly with professionals and failed to reflect families' existing views and priorities" (Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992, p. 208).

Recent evidence. More recently, evidence indicates that little has changed. "The Child-Study Team process is supposed to provide a network of support for children and prevent inappropriate referrals (Klingner & Harry, 2006, p. 2274). However, Lee-Tarver (2006) noted, "these teams provide less support for students at risk and serve more as a conduit for special education placement" (p. 525). In that vein, Klingner and Harry demonstrated that only "cursory attention was given to pre-referral strategies and that most students were pushed toward testing" (p. 2274). Additionally, these investigators noted that these meetings are "based on culture-deficit perspectives among school personnel who could barely conceal their contempt for parents who were marginalized and undervalued" (Klingner & Harry, 2006, p. 2274). Similarly, Wagner et al. (2012) demonstrated that participation in IEP meetings was "higher for parents of students with some kinds of disabilities than others, with some levels of income than others, and from some racial/ethnic backgrounds than others" (p. 152). Moreover, Wagner et al. found IEP meeting participation to be less than satisfactory for a significant number of parents of children with behavior challenges or poor social skills.

In addition to the above issues, Klingner and Harry (2006) also demonstrated that

the decision-making meetings lack the democratic aims of equal rights and opportunities for all individuals. These aims, codified by public education law (IDEA, 2004), ensure that schools will not discriminate or inhibit the rights of students regardless of their race, gender, or ability. Klingner and Harry further noted that while the federal law requires the child's parents and teacher to be equal members of the special education team, schools tend to marginalize the perspectives of parents and classroom teachers. Likewise, Schoorman, Zainuddin, and Sena (2011) supported this premise; their study indicates that CST meetings reveal unsettling patterns of silencing alternative perspectives and voices. These investigators demonstrated that psychologists tend to dominate the decisionmaking process and that there are "clear patterns of who was expected to speak and who was to remain silent" (Schoorman et al., 2011, p. 34). They found that the CST agenda is structured so that school specialists—specifically, the school psychologist—do most of the talking, and that time-allotted for parent or teacher input is minimal. These researchers concluded that "there was little expectation that the parent would speak" (p.34) and that "[parents] were there to listen, with little control over how the meeting would unfold" (Schoorman et al., 2011, p. 34). Heatherington et al. (2010) and Spann, Kohler, and Soenksen (2003) argued that meaningful parent participation is the exception, not the rule, particularly among parents of older students (Harry, Allen & McLaughlin, 1995). To that end, McLaughlin and Nolet (2004) reported that parental attendance is problematic, and parents frequently find themselves as receivers of professional information.

Last, Thoma, Rogan, and Baker (2001) report that special education meetings are "deficit-focused" (p. 26). Instead of discussing children from a strength-based

framework—what they do well—education professionals focus on what children lack in comparison to same-age peers. Moreover, educational jargon within these meetings is rampant, encumbering, and alienating to parents (Childre & Chambers, 2005; Spann et al., 2003). These authors described instances of hegemonic discourse—the way those who talk at any given time and place happen to be doing the talking (Jensen, 1994). Hegemonic discourse, according to Jensen, ripens or creates barriers of inequity and inequality for the child and his or her parents. The discourse is linguistically hegemonic because of the educational jargon and conceptual complexity within the discourse produced by the professionals. The discourse is also culturally hegemonic because of the established norms, mores, and discourses that define this meeting. Cultural hegemony means, for example, that knowledge and skill level subordinate parents, educational professionals dominate the discussion, and diagnoses, outcomes, and goals are frequently pre-established. In this vein, Tozer et al. (2009) argued that professionals, teachers, and administrators can create a dominant class ideology. They described how "wellintentioned" teachers in a hegemonic environment could become "complicit in reproducing...social inequalities" and reinforce the dominant ideology (p. 302).

In summary, the literature describes instances of cultural and linguistic hegemonic discourses. These problems within the special education process appear to be commonplace. They remain the status quo. Linguistic hegemony exists not only because of the educational jargon that is rampant in these meetings, but also because of the grammar rules inherent within the special education process framework: layman skill and knowledge regarding remediating the child's challenges subordinates parents. Cultural hegemony exists because of inherent power relationships: parents, who want their child

to be like his or her peers have apparently little say in the process; as such, they obligatorily defer to professional opinion. Thus, within the context of the special education process, there are social norms that establish the social structures. Intentionally or unintentionally, these structures are used by the ruling class (the professionals) to wield cultural dominance (the child's placement within the education system) and impose their worldview (the remediation program outlined in the IEP; Mouffe, 2000).

Problem Statement Summary

Breaking the news to parents about a child's impairments is a delicate process. It can be done well or not well. Likewise, discussing levels of performance or a plan of action for children with disabilities requires care and tact. That is, parents may feel alienated by confusing language, procedures, or paperwork that they must navigate within the formalized process of special education and disempowered by a perceived power difference between a "professional" and a "parent." Furthermore, if the discourse parents encounter is framed as a negative—a deficit-based view of their child—then parents may have feelings of marginalization. On the other hand, parents may feel empowered, united in cause, valued when the discourse is welcoming, strengths-based but has not glossed over or ignored the challenges that lay before the child, and encourages parents to be active team members. To best understand the dynamics of formalized special education processes and procedures, one must examine specific instances of parental perceptions surrounding the discourse that occurs. As researchers and my pilot study results suggest, this discourse can serve to privilege one party, empower, disempower, alienate and marginalize, or unite and value.

Unfortunately, when considering CDA, the literature fails to show the use of CDA to examine parent perceptions within or surrounding the special education process. This specific issue is illustrated and discussed in Chapter II, literature review. The absence of such literature, in my view, this justifies the need for this current investigation.

Research Purpose

The purpose of this study was to develop a grounded theory that describes and explains the discourse within the special education process of public education. Grounded theory is a "theory that is derived from data, systematically gathered and analyzed through the research process" (Strauss & Corbin, 1998, p. 12). My broad goal of this investigation is to understand and theoretically explain the derived perceptions of parents who have children with disabilities that arise from a set of entwined social and system complexities and constraints—the formalized processes and mores that define the process into special education. As such, I have interest in the discourse these parents experience and how it functions during critical moments of the special education process. I conducted a grounded, exploratory, multiple case study using tools of critical ethnography methodology such as CDA and similar outcomes involving empowerment. I conducted the study in this manner to accomplish multiple objectives. I wanted to understand the meaning of special education from the perspective of parents who have or have had children enrolled in special education. I also wanted to examine parents' experiences as they navigated special education processes, procedures, and mores while allowing the codes, categories, and themes to arise from obtained data. Last, I wanted to examine the encountered discourses through the process of CDA. My goal is to uncover,

identify, and label codes and themes that align with power relationships and elements of Critical Disability Theory while allowing for the possibility of other codes, themes, and explanations, a grounded theory standpoint. Do the discourses these parents experience function as a tool to empower or disempower? Whom does this discourse privilege? And last, do the discourses that these parents experience function to alienate and marginalize or unite and value? Is there an alternative explanation? More specifically, I ask:

Research Questions

When parents of children with disabilities experience critical moments of the special education process what is the discourse and how does it function to structure the experiences of parents? Why do the discourses function in the way they do and from those explanations, what is the theoretical model I can build?

I recruited two thirds of the participants (n = 10) from a state within the southwestern U.S. I recruited the remaining participants, one third (n = 5), from a state within the intermountain region of the U.S. Within the Southwestern area, there is a metropolitan city with an urban core and numerous suburban pockets. There are stark, notable differences in economic situations. There are also bilingual populations which predominantly include Hispanic individuals and Native Americans. Poverty is considered high. Crime, homelessness, drugs, gangs, poverty, a stagnant economy, illegal immigration, and high unemployment are all significant issues within this region. On the other hand, within the intermountain region state, participants were recruited from three rural areas and a suburban region of a large city. Most of the population in this region are monolingual and Caucasian. Crime, homelessness, and use of drugs are below the

national average, while poverty is slightly above the national average. The economy in this region, however, is healthy and unemployment is low.

Within the southwestern location, recruitment began in a suburban school district where I had received cooperation. This district, however, has fewer Hispanic and Native American individuals than the large neighboring metropolitan district; incomes and educational levels are also generally higher than the neighboring metropolitan district. Recruitment began in this suburban location as the metropolitan district denied cooperation; that is, I could not utilize district resources to recruit participants (parents of children with disabilities). Despite this denial, six of the fifteen participants, recruited via the snowball technique, reside within the boundaries of the metropolitan city school district.

Chapter Structure

In this dissertation, I present seven chapters. Within each chapter, I provide a brief introduction and end with a chapter summary. I try, in each chapter, to concisely restate the purpose of this study, my positionality, and how this research contributes to knowledge, policy, and practice concerning and within the special education process.

In the current chapter, I present my positionality and I introduce the reader to my pilot study that helped shape the practices and questions for this investigation. I also provide essential information concerning the history of special education and how it has paralleled the history of segregation. Additionally, I present the purpose, research questions, context, and type of study.

In Chapter II, I present the theoretical frameworks and conceptual contexts of this

grounded case study: I present and discuss a theory of impact known as Critical Disability Theory (CDT) and discuss the literature that surrounds it. In doing so, I also introduce and discuss Foucault's (2003) theory of power.

Following this discussion of CDT and Foucault, in Chapter II, I review four models of disability which include the social, minority, gap, and medical models of disability. Within this discussion, the reader will understand how CDA is an ideal tool or lens to view disability within any of these models and how the use of CDA as a tool is lacking.

In Chapter II, I also present parent perception research that is contextualized by special education. To do this, I introduce the reader to two reviews of the literature and then literature surrounding parent surveys, educational transitions, perceptions of membership, services in rural districts, and literature surrounding disability categories.

Last, in Chapter II, I present literature on significant themes that emerged during coding and the constant comparative analysis of the coded data. As this dissertation presents perceptions of parents surrounding the special education process, I recognize the need to respond to issues of leadership, dignity, power, equity and voice to name a few. With these ideas in mind, I intended to emphasize the relevance and value that parents provide when discussing educational concerns surrounding their children with disabilities. Thus, the next chapter will provide a review of the literature that yielded the theoretical conceptions behind my research. The thematic literature reviewed includes literature surrounding equity and equality as well as the concept of *voice*.

In Chapter III, I present the methodology surrounding this qualitative, grounded, exploratory, multiple case study design. I also explain the use of tools within critical

ethnography. In this investigation, "ethnography is both a process and a product" (Tedlock, 2000, p. 455). These two ideas are not exclusive but entwined. The participation of the participant, which allows them to voice their perceptions regarding special education processes, and the product, their voice. As a critical ethnographer, I study "social issues of power, empowerment, inequality, inequity, dominance, repression, hegemony, and victimization" (Creswell, 2012, p. 467). Importantly, as a critical ethnographer, I position myself in the text, being reflexive, self-aware of my role, and disclose biases and values (Creswell, 2012). While this is a non-neutral position, it allows me to advocate, as necessary, for the emancipation of marginalized parents and their children with disabilities within the current special education system. Also, importantly, in critical ethnography, "the data collection is less focused on time in the field or on the extent of data and more on the active collaboration between the research and the participants during the study" (Creswell, 2012, p. 478). Moreover, because critical ethnography may help bring "change that affects the lives of participants, the participants need to be involved in learning about themselves and steps [that] need to be taken to improve their equity, to provide empowerment, or to lessen their oppression" (Creswell, 2012, p. 478). The interview questions encouraged reflection on their attitudes, feelings, and beliefs as well as what they know and understand about the special education process; the questions also explored reflexively attitudes, feelings, and beliefs as well as what participants did not know and didn't understand about the special education process. As part of that reflexive process, I engaged in advocacy and education to reduce issues of marginalization or disempowerment. This engaged positionality aligns with the social justice component of CDT; it is a method for providing dignity to parents and their

children with disabilities (Mažeikienė & Ruškė, 2011).

As part of that critical ethnography discussion, I also explain in Chapter III the use of CDA, a tool within critical ethnography. I explain why CDA is necessary to examine perceptions held by parents whose children with disabilities are currently experiencing or who have experienced the special education process; that is, due to these meeting dynamics, there must be a critical examination of parental perceptions that surround formalized special education process discourses. These discourses may be hegemonic, and they may privilege, empower, disempower, alienate and marginalize, or unite and value. I utilized grounded theory as a standpoint for data analysis.

Within Chapter III, I also discuss how I use purposeful sampling (Glesne, 2011) to recruit participants for this grounded theory case study. Additionally, I detail some IRB modifications that were made to this investigation as it progressed due to difficulties that developed around district cooperation and participant recruitment. Within this research, I collected data in two forms: first, I utilized an online survey that explored perceptions and attitudes around aspects of the special education system as well as gathered demographic information; and second, I conducted a semi structured interview guided in part by survey responses as well as opened questions. In this study, I chose to utilize grounded theory methodology and critical discourse analysis to ensure a rigorous data analysis process.

In Chapter III, I also discuss the use of multiple case design, as well as the survey utilized in this investigation, the open-ended-semi structured interviews, and member checking I utilize to provide trustworthiness, authenticity, and credibility to this investigation. Multiple or repeated case study design is consistent with and an appropriate

tool for a grounded theory lens. Through this methodology, I focus on "developing an indepth understanding" (Creswell, 2012) of the special education process via the perspective of fifteen parents of children with disabilities who are currently engaged in or who have gone through the special education process. Regarding multiple case design, Yin (2003) wrote:

Each individual case study consists of a 'whole' study, in which convergent evidence is sought regarding the facts and conclusions for the case; each case's conclusions are then considered to be the information needing replication by other individual cases. Both the individual cases and the multiple-case results can and should be the focus of a summary report. For each individual case, the report should indicate how and why a particular proposition was demonstrated (or not demonstrated). Across cases, the report should indicate the extent of the replication logic and why certain cases were predicated to have certain results, whereas other cases, if any, were predicated to have contrasting results. (p. 59)

I used this logic and methodology behind multiple case design and within and across cases when engaged with participants and during critical discourse analysis and throughout the development of codes, themes, and relationships that arose from the participant's discourse.

Last, in Chapter III, I introduce participants by presenting aggregated and disaggregated demographic data as well as their primary concerns regarding their children with disabilities. I then turn to rich descriptions of each participant and provide their voice and story so that the reader can become familiar with each of the 14 participants are and their unique voices.

In Chapter IV, I begin to answer the primary research question. I document, through 34 perceptions- and attitudes-based research questions, the voice of fifteen parents who have children with disabilities. The avenue for this voice is forced-choice categorical response opportunities. This chapter establishes the concerns that parents with

disabilities have when engaging in and interacting with the special education process.

Through the survey, participants express their fears; they acknowledge their quality of life concerns for their children with disabilities. Most concerns centered around their child's ability to socialize and to communicate with peers and adults; they were less concerned with their child's quality of life in the school. Participants were more concerned about their child's ability to function at home and in the community. They also addressed how they might handle those concerns. Many participants stated that they would plan with the school and even more indicate that they would seek outside services.

As I demonstrate in Chapter IV, participants report their perceptions about obtaining support. Survey results reveal differences in the ability of my participants to effectively communicate with special education and general education professionals. They also report their attitudes about special education issues. Participants responded to questions about having a child with a disability versus seeing a child with a disability. They were also asked to put themselves in someone else's shoes and take on an 'other's' perspective. Responses to this question drew a direct relationship to participants' attitudes about labels uncovered in the interviews; this will be discussed thoroughly in Chapter V, Primary Themes. Survey questions also address the participant's view of the cost of specialized instruction, and I contrast those views to the equity received in having their children receive specialized instruction support.

Last, in Chapter IV, the concepts of power were addressed by participants through categorical responses. Participants responded to questions addressing power as repression, power as a social relation, and power as being productive. While most participants indicated that they felt they had the same voice, say, or authority in an

Evaluation Review meeting or IEP meeting, some participants indicate that they did not have the same power. They felt repressed, their voice unheard, and they did most of the listening. Responses to these questions draw a direct relationship to participants' discussions during the interview and their comments about feeling unheard.

In Chapter V, I detail findings of this study as they relate to the investigational questions. I document and describe the remarkably consistent codes, themes, and relationships that arose from the discourse of 14 of my 15 original participants. Within this analysis, I present six, clear themes that emerged from the 14 participants in this investigation. First, utilizing the word-frequency count within InVivo11, I demonstrate my participant's reactions within their discourse toward the special education process. The analysis shows that these participants are clearly 'frustrated' with the special education process. I then turn to the themes *Power*, *Advocacy*, *Dignity*, *Equity* and *Equality*, and *Voice*.

In Chapter VI, I present one-word summary perceptions that my participants expressed regarding the special education process and the justifications for those perceptions. From their summary perceptions, one surmises that critical moments of the special education framework challenged these individuals. These experiences have solidified into summary perceptions of that process.

The 14 summary perceptions presented in Chapter VI include *communicate*, confused, follow-through, lacking, frustrating, disheartening, cookie-cutter, overwhelming, 'They're doing their best,' effort, and useless. Participants provide explanations to these perceptions that directly connect to the research questions of this investigation. Briefly, to review, the focus of this research project surrounds parent

perceptions of the special education framework: I ask a multi-part question designed to look at the discourse that parents of children with disabilities experience. I intend to answer what is the function of the discourses these parents experienced, how the discourse functions as it acts on these parents, and to explain why the discourse functions in that exposed way.

Within Chapter VI, I also give my participants a voice through an empowerment question by asking them to identify what they believe needs to change with the special education process. From their background knowledge and experiences, participants easily answered the question. Remarkably consistent codes and themes emerged from their responses. These themes included better/more communication and more funding for tools, resources, and the quality and quantity of support personnel. They asked for more accountability and follow-through as well as for a shorter time span between referral, testing, and support. They also asked for specific quality characteristics of those serving children with special needs, including individuals who are open-minded, caring, and involved.

In the final Chapter, Chapter VII, I provide interpretations to the data obtained during this investigation and presented throughout Chapters IV, V, and VI. I discuss the survey results as they relate to the themes in Chapter V and VI. I also present the results with four models of disability available within the literature (presented in Chapter II), a model for improving equity within the schools (Kozleski and Smith, 2009) (also presented in Chapter II), and an ethical framework of leadership (Shapiro & Stefkovitch, 2005). I argue for a best-practice approach. I argue that a values approach and ethical framework could support the equity model of Kozleski and Smith (2009). This best-

practice approach could be utilized with any of the existing disability models so that reframing of the special education process can begin. I argue that this approach can mitigate a lot of equity and equality issues discussed within this document. Additional I provide a discussion regarding unanswered questions that require further research.

Chapter Summary

This chapter provides the reader with the scope, context, problem, and questions of this research project. For scope, I discussed the concepts of discourse, CDA, and hegemony. To summarize, discourses "function to maintain what does and doesn't get said and known" (Camicia, December 6, 2016, personal communication). While CDA is a methodology for addressing social problems through "relatively stable uses of language serving the organization and structuring social life" (Wodak & Meyer, 2009, p.6). Furthermore, hegemony "involves an all-encompassing system where "common sense" remains unexamined and inequitable systems go unquestioned" (Camicia, Dec. 6, 2016, personal communication).

Concerning context, I presented the reader a historical context of special education. I described and discussed common problems within the special education literature. In summary, the noted issues remain in in a state of status quo: there exists cultural and linguistic hegemonic discourse.

I identified the problem as the potential for parents to feel alienated by confusing language, procedures, or paperwork that they must navigate within the formalized process of special education and disempowered by a perceived power difference between a "professional" and a "parent." Moreover, if the discourse parents encounter is

negatively framed—a deficit-based view of their child—then they may have feelings of marginalization. On the other hand, parents may feel empowered, united in cause, and valued when the discourse is welcoming and strengths-based, an approach that presents what a child can do, and the program or programming builds around standpoint. A strengths-based approach means teams identify problems, but they do not view deficits a problem; in other words, they reframe the concept of deficits. They are a step to a child's strengths. A strengths-based approach encourages parents to be active team members. Therefore, to best understand the dynamics of formalized special education processes and procedures, one must examine specific instances of parental perceptions surrounding the discourse that occurs.

The questions, then, that drive this research project focus on the concepts of discourse and hegemony within the context of the special education process. I examine the function discourses plays through the perceptions of the parents who have experienced them. Using CDA, I build a theoretical model from the ground.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Overview

In Chapter II, I present the theoretical underpinnings of my positionality and I consider a theory of impact in this era of IDEA/ESSA. I also discuss four models of disability and how discourse, specifically CDA, has been lacking as a frame when considering the notion of disability from any of the available models.

From there, I turn to parent perception research that is contextualized by special education. To do so, I discuss past reviews of the literature, including that of involved parents and culturally and linguistically diverse parent perceptions. I also review the literature concerning parent perceptions concerning special education through literature based on survey work, transition research, membership literature, by location, and disability category.

Conceptual Context and Theoretical Orientation

In the following section, I present the conceptual context of a potential explanatory theory, a theory of impact known as Critical Disability Theory (CDT). Following this discussion, I turn to four models of disability that can apply to CDT, and specifically CDA.

To help better illustrate and frame the discussion presented in Chapter I, I too have been a witness to "well-intentioned" teachers. As an example, at a Student Support Team meeting that I attended at a school in which I taught, there was a lengthy discussion

concerning a Native American student with cognitive impairment. This student had been struggling with his current placement. He received instruction in a self-contained classroom. He had academics slowly provided. It also meant he was in a small class with structure. This student also interacted with general education students during specialty classes and activities like art, music, lunch, recess, and physical education. Meltdowns, however, were occurring at all transitions. The special education teacher in charge of that class spent the meeting blaming the child's upbringing, parents, and home environment as the cause of this child's difficulties in school. This teacher reported that she wanted to unilaterally change the child's label to "emotionally disturbed" due to the "uncontrollable" outbursts and "generally naughty behavior" without consulting the parent. Additionally, this teacher wanted the child "on a pill or something." In Chapter I, under the heading 'Historical and Contextual Framework of Disability Education' and subheading 'Recent evidence,' I discussed the investigation by Klingner and Harry (2006). These researchers found special education process meetings to be "based on culture-deficit perspectives" in which school personnel "could barely conceal their contempt for parents who were marginalized and undervalued" (Klingner & Harry, 2006, p. 2274). As I heard this veteran teacher speak, I thought that she could have been a subject of Klingner and Harry's investigation. This teacher spoke with contempt to other school members about the parents and child. She displayed a "culture-deficit perspective" of Native Americans. Her comments "marginalized and undervalued the parents and child" (Klingner & Harry, 2006, p. 2274).

I, however, spent the meeting questioning the teacher's assumptions, looking instead for differences between the child's culture and that of the school; I was using a

critical lens. I also asked questions about what the teacher had been doing to structure this child's environment so that the child could better predict from moment to moment what was to come next to support learning occurring within and the daily activities outside the classroom. Unfortunately, the meeting was rudderless—the building administrator was absent; as such, the discussion from my perspective was fruitless; I did not win favors by questioning this teacher in the manner I did.

This event reminds me of the authors Tozer et al. (2009) whom, in School and Society, encourage a focus on diversity and equity in the schools of today, and to meet the challenge of inequity through a theory of impact. These authors note that liberal theories "take for granted the existing social, economic, and political organization that has come down from classical and Enlightenment conceptions of humanity and society" (p. 419). They further state that critical theory "asks that we look not so much at the child or at the school, both of which function well in certain contexts, but at the relationship between the child and the school as the primary unit of analysis" (p. 420). More specifically, critical theory examines power relationships between two cultures, one of the child and one of the school. In doing so, one can expose conflicts, if any exist. One, then, views problems as a mismatch between the child and school rather than as a problem within the child (Tozer et al., 2009). Mismatch discovery opens the door for educators; it allows them the opportunity to create solutions so that the mismatch no longer exists. In many respects, it parallels the multicultural education reform movement described by Banks (1992), "...a reform movement designed to bring about educational equity for all students, including those from different races, ethnic groups, social classes, exceptionality, and sexual orientation" (p. 21). One of the goals, then, of a critical

theorist, is to develop, seek, or utilize teaching methodologies and strategies that assist or provide certain groups of students who are on the deficit end of power relationships so that education becomes accessible.

Using a critical theory lens, Knapp (1995) investigated successful teaching strategies in use for children who resided in high-poverty classrooms—classrooms disproportionately populated by students of color. These researchers tied strong academic learning gains in children experiencing poverty to teachers who did three things well: maintain classroom order, respond effectively to diverse cultural backgrounds, and *teach for meaning*. That is, teachers use approaches designed to engage students and utilize their higher-order thinking skills to make connections between academic learning and their life experiences. Teachers who teach for meaning reject a traditional focus on student deficiencies and the traditional emphasis on learning discrete skills (Knapp, 1995). It means that instructional strategies should stimulate and challenge the student. Similarly, Marzano (2003) recommends high standards, a clear sense of direction, ongoing curriculum development, teachers involved in all stages of planning, and drawing parents and community into the teaching process.

In sum, then, professionals, teachers, and administrators can create a dominant class ideology (Tozer et al., 2009). When this occurs, they marginalize the voice of parents and their children with disabilities (Klingner & Harry, 2006). A potential explanation for this is CDT; those who follow this theory find disability to be a social construct, rather than "the inevitable consequence of impairment" (Hosking, 2008, p. 7). The need for such a construct is bolstered by Anderson (2006) who stated "...there has been limited consideration of disability in critical pedagogy. This omission of people

with disabilities is puzzling given critical pedagogy's commitment to disrupt oppressive practices in the classroom and society at large" (p. 374).

CDT takes its shape from the impact of pervasive discrimination, prejudice, assumptions, institutions, and structures that create disadvantages for persons with disabilities (Devlin & Pothier, 2006). The idea, then, of combining disability and critical pedagogy "is powerful, not just for the people it might empower, but the impact disability could make on the practice itself" (Butte, 2010, p. 171). "Disability" as Anderson (2006) indicated "is not just another specialty with concerns loosely related to other minorities. The experience of disability is relevant to all marginalized groups-for all groups have people with disabilities in them" (p, 367).

Through CDT, then, disability is a relationship between impairment, an individual's response to impairment, and the social environment (Hosking, 2008). As such, CDT highlights the social disadvantages experienced by those with disabilities, including those that are "physical, institutional, and attitudinal" (Hosking, 2008, p. 7). CDT is a member of the *Critical Theory* family: it is "explanatory," "practical," and "normatively objective" (Hosking, 2008, p. 3). Moreover, as a member of the critical theory family, CDT is used to "explain what is wrong with current social reality, identify the actors to change it, and provide both clear norms for criticism and achievable, practical goals for social transformation" (Bohman, 2013, p. 2).

With that in mind, Nocella (2008) argues that disability study provides "a location and a means to think critically about disability, a juncture that can serve both academic discourse and social change" (p. 77). According to Nocella, CDT is a tool for challenging the adequacy, content, and structure of a curriculum. To this description, I add that CDT

is a vehicle for "resisting the harmful effects of dominant power" (Kincheloe, 2008, p. 10); in other words, CDT is a tool for challenging the pervasive problems within current special education practice as presently described. Moreover, with CDT, one can ask "not only the traditional question of what is to be done but also who is to do it?" (Devlin & Pothier, 2006, p.12): through CDT, one pursues a politics of transformation. Thus, by understanding disability as a socially created barrier, transformation shifts from the individual to the responsibility and accountability of the larger community (Baker, 2006; Rioux & Valentine, 2006). Practically speaking, instead of focusing on prevention, cure, or rehabilitation of the individual, CDT makes "a person a person through other persons" (Shutte, 1993, as cited in Kabeer, 2002, p. 37). CDT, then, is a method for providing dignity to parents and their children with disabilities (Mažeikienė & Ruškė, 2011).

This discovery is at the heart of critical pedagogy, as well as CDT. It focuses on the "understanding and use of knowledge" (Kincheloe, 2008, p. 10) so that "educators and teachers [can] reconstruct their work, so it facilitates the empowerment to all students" (Kincheloe, 2008, p. 9). Knowing, then, that educational jargon, deficit-based views of children, and Power differences between a "professional" and a "parent" are alienating, one can work to reframe discourse within these contexts or in other environments as they occur.

Importantly, Foucault (2003) links the concepts of critical theory or specifically CDT, to the concept of power when he discusses power relationships and disciplinary knowledge. To Foucault (2003), power is "repression" (p. 43), using lepers and those with the plague to exemplify his point. Foucault states that the mechanisms of power held over these individuals—one of repression—results in "exclusion, disqualification, exile,"

rejection, deprivation, refusal, and incomprehension" (p. 44). If we consider Foucault's *power of repression* within the CDT framework and a hegemonic school system context, then parents and their children with disabilities may find themselves an object of "exclusion, disqualification, exile, rejection, deprivation, refusal, and incomprehension" (Foucault, 2003, p. 44).

A second point that Foucault (2003) makes concerning power is that it is not a thing, but a relation; for Foucault, power operates at the most micro levels of social relations. As such, it is omnipresent at every level of the social body (Foucault, 1990). Additionally, Foucault (1980), in describing disciplinary knowledge, stated that under the guise of scientific objectivity, disciplinary knowledge has been integral to networks of social control even when they have been deemed progressive or independent of power. In my view, this point from Foucault is akin to the cultural hegemony issue mentioned earlier: that is, within the context of the evaluation review/IEP meeting, there are social norms that establish the social structures. These inherent structures are used by the ruling class, in this case, the professionals, to wield cultural dominance—specifically, the child's placement within the education system—and impose their worldview, the remediation program outlined in the IEP (Mouffe, 2000).

Last, regarding *power*, Foucault (1990) states that power is not only repressive or is a relation, but it can also be productive. If this is the case, then, reframing the hegemonic discourse of the special education process to one that is productive may create an environment that invites a strengths-based understanding of the child in question as well as a democratic style of leadership, advocacy, and collaboration between all members of the including parent and child. Ultimately, this goal or understanding can

help us improve information delivery and lessen or ameliorate the alienation, marginalization, and power inequities parents may encounter.

Models of Disability

In considering models of disability and critical discourse analysis, Featherman (2016) wrote, how "we talk and think about disability might be, perhaps paradoxically, revealed in how we commonly conceptualize understanding" (p. 137). Featherman aptly illustrated this quote by discussing Vidali (2010) and the metaphor, "knowing is seeing" (p. 137). This metaphor "entails that blindness, a physical impairment, is misunderstanding—in other words, a deficit and deviation from the norm" (p. 137). Within this discussion of metaphors, Featherman added through the voice of Vidali that as there are creative ways to use language, there are also creative ways to rethink and reframe how we think about disability. At this point, however, four conceptualizations of disability exist in the literature. These include the social model, the minority model, the gap model, and the medical model (Grue, 2011; see Figure 1).

Social model. The *social model of disability* emerged from Marxist sociology. From this standpoint, disability is a form of political or economic oppression. In

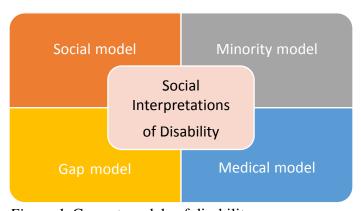


Figure 1. Current models of disability.

discussing the work of Barnes, Mercer, and Shakespeare (1999) and Oliver (1990, 1996a, 1996b), Grue (2011) noted that this oppression is "enacted on people whose bodies do not conform to the needs of industrial capitalism" (p. 538). According to Grue, with the social model, one can closely examine the "systemic factors that shape the meaning of disability, particularly those that have to do with political economy" (p. 538). As such, with the social model of disability, one could, for example, examine constructed space (the architecture that divides individuals with disabilities from those without disabilities) or resource allocation in the schools for the mass of children without disabilities and the few who require specialized instruction. Grue, in discussing Shakespeare (2006) noted, however, that those who utilize the social model of disability are reluctant to acknowledge aspects of disability or theorize "impairment as a bodily and embodied phenomenon" (p. 538).

Minority model. A second model of disability, the *minority model*, emerged from activism here in the U.S. that centered around the civil rights movement, activism against discrimination resulting from race and ethnicity (Grue, 2011). In discussing Breivik (2007), he wrote that with the minority model, "disability is explained as...a form of cultural otherness" and is exemplified by many individuals who are Deaf (Grue, 2011, p. 539). He adds:

The capital D is intended to mark deafness as a cultural and linguistic identity, one, which in the USA, is strongly tied to Gallaudet University, established in 1864 as the world's first institution specifically designed to accommodate the deaf and hard of hearing. Some Deaf people and organizations wholly reject the disability label, seeking instead parallels with gay and lesbian communities. (p. 539)

Grue (2011) also discussed Antonetta (2005) who provided the example of

individuals with autism spectrum disorder who promote "neurodiversity as a marker of cultural identity" (p. 539). The challenge with the minority model is that it does not explain well "the continuing economic and political marginalization" of people with disabilities (Grue, 2011, p. 539).

In discussing the minority model further, Grue (2011) presupposed that the minority model appeals to individuals who might have a hidden disability or those that consider their impairment "a form of biological difference to be valued, not 'fixed' or 'healed'" (p. 539). He notes that disability, for many, is undesired, and "not something to be put at the forefront of their social identity" (Grue, 2011, p. 539).

Gap model. The third model of disability is known as the *gap model of disability*. In this model of disability, there is an acknowledgment that "a proportion of the population will at any given time have either impairments or illnesses that place certain restraints on their functional capacities" (Grue, 2011, p. 540).

Disability, then, is the gap. It is the gap between ones' capacities and societal and institutional opportunities (Darling-Hammond, 2010; Grue, 2011). Specific policy measures placed on society, institutions, schools, and employers can reduce or close a disability gap, removing or lessening the notion of disability (Grue, 2011). In discussing Barne-og likestillingsdepartementet (2008), Grue noted that use of this model makes one "aware of state bureaucracies in the social construction of disability" (p. 540).

Medical model. The final model of disability is the *medical model*. Grue (2011) stressed that it is "difficult to find any discussions that are not critical or wholly dismissive of it" (p. 540). Grue (2011) also stated that with the medical model, one sees:

The reduction of various aspects of disability to medically recognized

phenomena. The medical model is, however, the nemesis of advocates that employ all three models discussed above. It is described as an ideological framework that reduces every aspect of disability to bodily impairment, prescribes only medical treatment and normalization as appropriate interventions, and denies agency to disabled people while reserving power for medical professionals (p. 540).

Grue (2011) questions the wisdom of those who continue to refer to the practices and procedures within medical professions as a model. He states, "at least outside of historical studies, because the end result of this strategy may be to keep alive the illusion that it provides a theoretically viable perspective on disability (p. 540)." In considering all four models of disability, then, Grue (2011) noted that they all fail to provide a full account of disability. Regarding the social, minority, and gap model of disability, he wrote:

The social model does not properly acknowledge biophysical causation; the minority model does not account for economic and political causation; and the gap model assumes to a utopian extent that the gap between ability and expectation can always be closed—that there is no need for a distinct social role of disability. (p. 541)

The medical model, as noted above, is treated separately by (Grue, 2011). He stated that this model "is usually articulated so as to be invalid as an explanatory instrument by definition" (p. 541).

pervasive within the U.S. special education framework.

³ As a speech-language pathologist with a Certificate of Clinical Competence and has worked for both

medical agencies and Canadian and U.S. School systems, I question Grue's (2011) dismissive nature of the medical model. One cannot dismiss it; at least not yet. Within the special education framework, its use is pervasive. Currently, special education team members use this model to categorize and classify (label) children with a disability due to IDEA and NCLB and the inherent structure that these laws impose. For example, psychologists use the DSM V to demarcate a diagnosis. Likewise, during evaluation review meetings, there is discussion with the parent on how far their child deviates from the mean concerning a given set of examined skills. Moreover, when I bill school-based Medicaid for speech-language services rendered, I must use ICD-9 (medical codes) as a point of connection with that agency. While I agree with Grue (2011) that this model is abhorrent, and we should abandon it, it is also

Discourse Research and Disability

In my view, the absence of literature that utilizes CDA to examine parent perceptions of the special education process justifies the need for this current investigation. To illustrate this lack of literature (see Figure 2), I present the number of accessible, English, peer-reviewed journal articles from 2007 to 2017. These articles focus specifically on CDA and identity markers. The identity markers included were gender, race or ethnicity, class or SES, and disability. For this search, I utilized Utah State University's library database system.

My rationale for doing this was to see how various academics utilized CDA concerning identity markers, which includes disability. To access these articles, I utilized ERIC (Education) via EBSCO Host. To capture the entirety of possibilities, I checked all databases. For the identity marker gender when paired with CDA, I located 836 articles; for race or ethnicity and CDA, I located 718 journal articles; for class or SES and

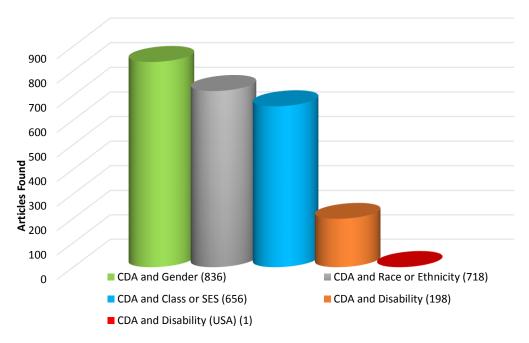


Figure 2. Identity marker incidence and CDA in peer-reviewed journals (2007-2017).

CDA, I located 656 articles; and last, when I paired disability with CDA, I located only 198 articles. When this search was limited to academic, peer-reviewed journals within the U.S., the search revealed only one article (Grenier, Horrell, & Genovese, 2014). Grenier et al. discussed CDA and disability from the perspective of physical education teachers with disabilities. Within education in international journals, CDA has been used as a tool to examine co-teaching from a Disability Studies in Education perspective and to analyze power and discursive dominance in an inclusive coteaching arrangement (Randhare Ashton, 2014). CDA was also a tool for research conducted by O'Brien and Placier (2015). These researchers conducted an ethnographic case study of a state-funded residential school for the Deaf and utilized CDA to identify competing discourses in the talk of educators. O'Brien and Placier discussed how there is a discourse rooted in oppression and labeling of individuals who are deaf or hard-of-hearing as disabled and an opposing discourse that stems from Deaf culture. A third investigation by Jordan (2008) examined teachers' discursive communication surrounding African American youth. In her discussion. Jordan wrote:

Because discourses contribute to the construction of social identities and subject positions (Fairclough, 1992), they hold implications for both teachers and students. Throughout the interviews conducted as part of this study, teachers' discourses, their explanations of student performance and needs, positioned students in a variety of ways: emotional, at risk, disabled, controlled by hormones, and affected by family issues/poverty. These discourses, in effect, limit teaching possibilities and, therefore, students' learning opportunities. (pp. 10-11)

These results, as Jordan (2008) suggested, indicate that reform success is tied to a practitioners' willingness to "acknowledge and examine critically the discursive assumptions (both institutional and societal) and practices that unfairly disadvantage Black youth" (p. 11) regarding educational inequities tied to race.

CDA has also been utilized to analyze written responses of teacher candidates writing in response to interview questions surrounding disability. Stamou and Padeliadu, (2009) demonstrated that the CDA of the written accounts revealed that candidates used both traditional (medical) discourse and progressive (social) discourse. However, the traditional discourse subjugated the progressive discourse.

Avissar, Licht, and Vogel (2016) utilized CDA to examine the perceptions and attitudes surrounding inclusion of various leaders within the Ministry of Education in Israel who are responsible for constructing policy. The researchers demonstrated that the discourse revealed differences between and within groups of these leaders regarding "identification of the target population, factors and key figures affecting implementation, and teacher training" (Avissar et al., 2016, p. 973).

For adults with intellectual disabilities, CDA has been utilized to examine media accounts of parenting and disability (Fraser & Llewellyn, 2015). Using CDA, these researchers reported that found that

...discourses of care and child protection are emphasized in news articles about parenting, creating perceptions that negate the role of people with disabilities as parents. Such perceptions result in a systematic symbolic castration of people with intellectual disabilities from the role of parent in Australian society. (p. 319)

The arena of mental health disabilities also utilized CDA. Galasiński (2011) employed CDA and ethnography in mental health settings. Ethnographically, Galasiński explored the practices of Polish psychiatric hospital and contrasted the accounts of patients with a depressive disorder after their admission to a hospital ward. Galasiński argued for the analysis of discourse, stating that it is crucial to ethnographic study. Galasiński stated that through "microanalysis of such stories, one which will not only be

informed by the ethnography but also, crucially, inform it" (p.257). As such, Galasiński suggested not replacing "ethnography by discourse analysis, or the other way around, rather a joint venture which will allow for a two-way passage of information and will show mental health provision in its full complexity" (p. 257).

In considering CDA as a methodology for analyzing disability, Grue (2009) wrote that "much of the concern with discourse in the disability field" is that "the word 'disability' is ambiguous" regarding causation (p. 288). Grue added:

Different causal models are strongly linked to different discourses. While most definitions specify the condition of being disabled as lacking the ability to do something, that lack of ability may be considered as, variously, 1) a *restriction*, 2) a *disadvantage* or 3) an *inability*. The range of specifications progresses from 1) something imposed (socially, environmentally or politically) from without, via 2) something more akin to a predicament or situation, to 3) something (medically) intrinsic to an individual, and so implies different remedies. The controversy over what policies to adopt has often taken the form of arguments over words. As one example, there has been extensive debate over whether 'people with disabilities' or 'disabled people' is the preferred usage. In the disability field, as in critical discourse analysis (CDA), language is seen as both a symptom and cause of *social change*. (p. 288)

To move forward, Grue (2011) suggested that CDA be the tool or method for discovering how to better frame and theorize about disability. He stated that CDA might reveal how the current models of disability grew from different discourses. Moreover, it can provide an outside, fresh perspective (Grue, 2011). Furthermore, CDA can reveal how and where to reconsider the current models of disability (Grue, 2011). Last, Grue stated that one could use "legislation, codes, and regulations in the public, private, and civil sector" (p. 544) with CDA.

Discourse research and disability summary. This investigation is guided by a view that discourse (language use in speech and writing—is "...a form of 'social

practice" (Fairclough & Wodak, 1997, p. 258; S. Hall, 2001). It is central to the production and interpretation of meaning. CDA, then, according to Jordan (2008) "establishes a framework for researching social practice through critical language analysis" (p. 6).

The assumption behind CDA is that individuals shape their social world through encountered social practices. These social practices are, in turn, "shaped and constrained by norms and beliefs that exist in tension among competing discourses" (Jordan, 2008, p. 6). In this regard, discourse, language use in speech and writing, is a form of social practice. It can perpetuate or break systems of knowledge and belief.

When one considers major societal, social platforms (e.g., schools, the education system, the special education process framework), the encountered discourses are deeply embedded. "These discourses facilitate particular ways of representing and signifying meaning" (Jordan, 2008, p. 6). As an example, there is the discourse of referral to special education. When a referral occurs, a teacher begins to construct an identity of the student—one of disability. This identity is institutionally sanctioned at the school, district, state, and federal levels. Moreover, this discourse can be internalized by teachers. That is, they may practice referral uncritically, not understanding that they are reproducing or perpetuating a discourse that may negatively affect a child and the parent of that child who also encounters that discourse. As such, the lack of literature surrounding CDA, disability, and perceptions of parents, presents the need for this investigation.

As there was no literature on CDA, disability, and perceptions of parents, I turned to other literature surrounding the special education process and parent

perceptions. I present this literature in the following section.

Parent Perception Research Contextualized by Special Education

I conducted a review of the literature using ERIC via EBSCO host. I expanded the search from ERIC (an education database) to include all available databases through Utah State University. This expansion allowed me to capture literature outside the field of education. I utilized the following terms while searching: parent perceptions or parent attitudes and special education or Individual Education Plan. To the term special education, I also tried qualifiers including special education or Individual education process and procedures. The search also involved the terms qualitative investigation or survey as well as the terms parent empowerment or parent involvement in special education. Articles included in my literature review are limited to the past 20 years (1997-2017). I included any previous reviews of the literature found between 1974, following the enactment of public-law 94-142, and 2017. I excluded parent perceptions of early intervention, and Individual Family Service Plans (IFSPs), as these are not the focus of this investigation. I included the transition to preschool-based services, elementary, and secondary education. I allowed quantitative, survey, and qualitative literature.

While conducting the literature review, I categorized literature in the following manner: Parent perceptions of the special education process through the lenses of *survey literature*, *culture/SES/ethnicity literature*, *transition literature*, *membership literature*, *disability category literature*, and *rural/urban literature*. I found no investigation that was (a) qualitative, (b) investigated parent perceptions of the special education process between the years 2007 and 2017, (c) or had the same research questions and purpose.

Thereby the need for this research project is supported by the lack of literature specific to this current investigation. While conducting the literature review, however, I found research that examined pieces or elements of my research interest and topic. These will be reviewed and discussed below:

Past reviews of the literature. Within the search, I found two systematic reviews of the literature. The first systematic review concerns perceptions of "involved" parents' within school-based team meetings (Esquivel, Ryan, & Bonner, 2008). The second systematic review covers culturally and linguistically diverse parents' perceptions of the special education process (Wolfe & Durán, 2013). I discuss these two works in turn.

Review of 'involved' parent perceptions. Esquivel et al. (2008) found and reviewed 12 studies from the period of 1980 to 2008. These studies include Fleming and Monda-Amaya (2001); Gallagher and Malone (2005); Goldstein et al. (1980), Goldstein and Turnbull (1982); Huebner and Gould (1991); Witt, Miller, McIntyre, and Smith (1984); Shriver and Kramer (1993); Slonski-Fowler and Truscott (2004); Spann et al. (2003); Truscott, Cosgrove, Meyers, and Eidle-Barkman (2000); Vaughn, Bos, Harrell, and Lasky (1988); and McNamara, Telzrow, and DeLamatre (1999). Of these 12 studies, however, only seven involve specifically the perceptions of parents. The remainder concerns perceptions of parents from the perspective of other team member professionals. Parent perception specific studies in the work by Esquivel et al. (2008) included Goldstein et al. (1980), Goldstein and Turnbull (1982), Witt et al. (1984), Vaughn et al. (1988), Shriver and Kramer (1993), McNamara et al. (1999), and Spann et al. (2003). I discuss these investigations chronologically, beginning with the oldest (see Table 1).

Table 1

Review of "Involved" Parent Perceptions (Esquivel et al., 2008)

Citation	Participants	Purpose and procedure	Relevant findings
Goldstein et al. (1980)	14 parents of children in grades 2 through 6 with learning disabilities	(a) Coding of speaker, recipient, and topic during 14 IEP conferences; (b) 8-item Likert questionnaire assessing parental satisfaction	(a) The resource teacher frequently spoke in 11 IEP meetings; (b) The only two meetings in which parents talked more frequently were meetings in which fathers (not mothers) participated.
Goldstein & Turnbull (1982)	45 parents of children with learning disabilities	(a) Three groups of parents ($n = 45$). A third completed questionnaires about their child's goals, academic potential, and IEP; a third were given an advocate at each IEP conference; a third received no intervention. (b) They coded frequency and reason for parental contributions during IEP conferences. (c) Parents completed a parental satisfaction questionnaire regarding participation, IEP conferences, and the IEP.	Parents who had an advocate were more involved during the meeting than were parents receiving no intervention.
Witt, Miller, McIntyre, & Smith (1984)	243 parents of children with special needs	23-item scale assessing parental participation in and satisfaction with team meetings	Parent satisfaction was related to sufficient meeting time, team members contributions, parent contributions, and not blaming parents for children's problems.
Vaughn et al. (1988)	Parents of 26 elementary students with suspected learning disabilities	(a) Coding of parents' questions, spontaneous comments, and responses to comments or questions during initial IEP meetings(b) Structured interview with parents	(a) The average length of meetings was about 41.5 min; (b) Of the 41.5 min, parents interacted for about 6.5 min; (c) Most parents (69%) felt positive about the initial IEP meetings.
Shriver & Kramer (1993)	181 parents	a 35-item questionnaire assessing parents' perceptions of children's initial evaluations, the MDT process, and involvement in IEP planning.	Parents were satisfied with the evaluations, MDT process, and involvement in creating IEPs.

Citation	Participants	Purpose and procedure	Relevant findings
McNamara, Telzrow, & DeLamatre (1999)	185 parents	(a) 13-item attitudinal survey regarding involvement and satisfaction; (b) Student goal attainment score, reflecting the extent to which students achieved goals, as rated by two school psychologists.	(a) Goal attainment did not predict parental perceptions of children's school performance improvement. (b) Parental reports of supporting interventions at home predicted goal attainment.
Spann et al. (2003)	Parents of 45 children (ages 4–18) with autism spectrum disorder	15-item questionnaire via interview including three questions about knowledge of, involvement in, and satisfaction with child's IEP,	87% of parents reported moderate involvement in the IEP process; 86% reported moderate satisfaction with the IEP process; several parents indicated a lack of participation in IEP because of IEP predetermination.

In the first study reviewed by Esquivel et al. (2008), Goldstein et al. (1982) investigated 14 parents of children with learning disabilities who were in grades two through six. These researchers coded the speaker, recipient, and topic during IEP conferences. Additionally, they had an eight-item Likert scale to gauge parental satisfaction. Goldstein et al. found that special education teachers spoke the most in 11 of the 14 meetings. In two meetings in which that did not occur, a father attended, not the mother.

In the second study from Esquivel et al., Goldstein and Turnbull (1982) investigated 45 parents of children with disabilities. Three groups divided the parents. The first group filled out a questionnaire which encompassed goals for the child, goals for the IEP, and the child's academic potential. The second group had a parent advocate at the IEP conference, a guidance counselor. The third served as a control. This group had no intervention. Goldstein and Turnbull found that those parents who had a guidance counselor (an advocate) were more involved during the meeting than were parents receiving no intervention.

In the third investigation, Esquivel et al. (2008) reviewed Witt et al. (1984). These investigators gave a 23-item scale assessing parental participation and satisfaction of IEP meetings to 243 participants. They tied parent satisfaction to the amount of meeting time, contributions from team members and parents, and through team members not blaming parents for their children's problems.

In the fourth investigation from Esquivel et al. (2008), Vaughn et al. (1988) studied parents of 26 elementary students suspected of having a learning disability. These

researchers coded parents' questions, their comments, and their responses to questions during initial IEP meetings. They also conducted structured interviews with parents.

Vaughn et al. (1988) that parents interacted in an IEP meeting for an average of 6.5 minutes out an average 41.5 min meeting length. They also found that most of the parents (69%) felt positive about these meetings.

The fifth investigation from Esquivel et al. (2008) that explored parent perceptions and perspective was a study from Shriver and Kramer (1993). In this study, these researchers had 181 parents complete a 35-question survey covering initial evaluations, the MDT process and the parents' involvement in planning IEPs. Shriver and Kramer found that parents were satisfied with all aspects investigated. As reported in Esquivel et al. (2008), McNamara et al. (1999) also explored the perceptions of parents' perceptions through a 13-item survey and a goal-attainment rating score completed by the school psychologists. McNamara et al. found that student goal attainment was not a predictor of parental perceptions of their children's school performance improvement; however, parental support in the home was a predictor of goal attainment.

The final investigation reviewed by Esquivel et al. (2008) that was specific to parents' perceptions was an investigation by Spann et al. (2003). These researchers examined perceptions of 45 parents of children with autism or other pervasive disorders, aged four to eighteen, through a survey that targeted parents' knowledge, involvement, and satisfaction with their child's IEPs. Spann et al. reported that 87% of the parents indicated at least moderate involvement in the IEP process, 86% were moderately satisfied, and several parents stated a lack of participation due to beforehand creation of

the document.

In summary, these seven studies spanning 1980 to 2005 were Likert-style surveys of various aspects of parental perceptions. However, Esquivel et al. (2008) reported no qualitative case studies of parent perceptions from the period under their review.

Review of culturally and linguistically diverse parents' perceptions. Wolfe and Durán (2013) reviewed nine investigations that concern the perceptions of culturally and linguistically diverse parents. Wolfe and Durán reported that three investigations focused on the IEP process while six involved both the IEP process and special education services. Of these nine studies, four were specific to Latino parents (Hardin, Mereoiu, Hung, & Roach-Scott, 2009; Hughes, Valle-Riestra, & Arguelles, 2002; Lian & Fontanez-Phelan, 2001; Salas, 2004). Wolfe and Durán found three focused on Korean American parents (Cho & Gannotti, 2005; Park & Turnbull, 2001; Park, Turnbull, & Park, 2001). These investigators located one article that examined the perceptions of Chinese American parents (Lo, 2008) and one investigation looked the perceptions of Latino, African American, and White parents (Hernandez, Harry, Newman, & Cameto, 2008). From this group of nine investigations, Wolfe and Durán identified six that had recurring, consistent themes. Following identification, these authors synthesized those articles. They included research by Cho and Gannotti (2005), Hardin et al. (2009), Lo (2008), Park and Turnbull (2001), Park et al. (2001), and Salas (2004) (see Table 2). According to Wolfe and Durán, the remaining three investigations were outliers and as such discussed them separately. These outliers are Hernandez et al. (2008); Hughes et al. (2002), and Lian and Fontanez-Phelan (2001).

Table 2 Review of Culturally and Linguistically Diverse Parents' Perceptions (Wolfe & Durán, 2013)

Citation	Population	Sample size	Income level	Proportion with limited English proficiency	Geographic location	Method	Disrespect	Negativity toward child	Lack of information	Language barriers	Communication barriers	Cultural Barriers
Park & Turnbull (2001)	Korean American	8	NR	NR	WA, VA	Telephone interviews			X	X	X	X
Park et al. (2001)	Korean American	10	70% Mod. to High	50%	WA, IL, VA	Telephone interviews	X	X	X	X	X	X
Salas (2004)	Latino (Mexico)	10	100% low	100%	Southwest Border	Interview	X	X	X	X	X	X
Cho & Gannotti (2005)	Korean American	20	15% Low	45%	Southern CA	Interview	X	X	X	X	X	X
Lo (2008)	Chinese American	5	NR	80%	MA	Observation, interview	X		X	X	X	X
Hardin et al. (2009)	Latino	5	NR	NR	NC	Focus groups			X	X	X	
Lian & Fontanez-Phelan (2001)	Latino (Mexico, Caribbean, Cen. & S. America, USA)	100	NR	73%	Midwestern state	Survey				X		

Citation	Population	Sample size	Income level	Proportion with limited English proficiency	Geographic location	Method	Disrespect	Negativity toward child	Lack of information	Language barriers	Communication barriers	Cultural Barriers
Hughes et al. (2002)	Latino (Caribbean, Cen. & S. America, USA)	44	NR	46%	NR	Questionnaire (interview: <i>n</i> = 16)			X	X		
Hernandez et al. (2008)	African American, Latino, White, Other	1417	Low, moderate, High	68%	Southern CA	Survey	NA	NA	NA	NA	NA	NA

The major themes of these six investigations include *Disrespect for the parent*, negativity toward the child, insufficient information, and Language, Cultural, and Communication Barriers (Wolfe & Durán, 2013) with at least three of the six themes reported by each of the six investigations. I discuss each theme briefly below.

Barriers to communication and language were themes reported within the investigations reviewed by Wolfe and Durán (2013). Wolfe and Durán found these themes in eight of the nine studies reviewed. These investigations include Cho and Gannotti (2005), Hardin et al. (2009), Hughes et al. (2002), Lian et al. (2001), Lo (2008), Park and Turnbull (2001), Park et al. (2001), and Salas (2004). Barriers included a professional's use of jargon, differing styles of communication, level of English proficiency, and lack of interpreters or, at the very least, lack of an appropriate interpreter. For example, Wolfe and Durán reported that interpreters were often first-generation immigrants whose English was not sufficient. Furthermore, participants also discussed lack of verbatim translation due to meetings that moved too quickly and interpreters who devalued comments made by parents while valuing those made by professionals (Wolfe & Durán, 2013).

A closely related theme to barriers of communication and language was identified by Wolfe and Durán (2013) as *insufficient information*. This theme was present in seven of the studies reviewed (Cho & Gannotti, 2005; Hardin et al., 2009; Hughes et al., 2002; Lo, 2008; Park & Turnbull, 2001; Park et al., 2001; Salas, 2004). Within this theme were parents unprepared for the IEP meeting due to their lack of knowledge about procedures, structure, and logistics (Wolfe & Durán, 2013). Moreover, Wolfe and Durán reported that

this theme included parents who "felt as they were not sufficiently informed about their child's disability or educational program options" (p. 11). This concept presents itself throughout the results of this dissertation. The supporting evidence occurs through survey responses (Chapter IV) and as an element of the theme *Power* (Chapter V). It also presents itself through parent summary responses as my participants discuss *Communication, Frustrations*, in special education process elements that they described as *Lacking*, as well as in my participant's desires for special education reform (Chapter VI). All adding to the credibility of my results. Wolfe & Durán further report that parents within many of the studies reviewed reported feeling nervous or intimidated by the language, communication, and information barriers present. Likewise, these same perceptions were revealed in the discourse of my participants, further strengthening result credibility of this dissertation.

Interestingly, my results diverge from those reported by Cho and Gannotti (2005) who discussed Korean American parents who had attended IEP workshops and training. Despite efforts from these parents to effectively advocate for their children, they were unable. My participants, thirteen of which reported themselves as Caucasian, were mostly successful once training and advocacy had been initiated (even though it wasn't easy), indicating a genuine lack of cultural sensitivity as reported within these reviewed investigations. Not surprisingly, *Barriers of culture* was a clear theme that Wolfe and Durán (2013) described. Five of the nine studies contained that theme, specifically, Cho and Gannotti (2005), Lo (2008), Park and Turnbull (2001), Park et al. (2001), and Salas, (2004).

In Cho and Gannotti (2005), Lo (2008), Park and Turnbull (2001), and Park et al. (2001), the investigators Wolfe and Durán (2013) reported a perceived *disrespect toward parents*. These researchers stated that as parents discussed their interactions with professionals, parents perceived disrespect most commonly from as a devaluing of parental expertise and a lack of recognition. I confirm these specific thematic results through my findings. Many of my participants reported that the professionals that they interacted with did not listen to their concerns or that they described having a voice without a voice. Individuals within the special education process directly challenged the roles of my parents as an expert or advocate for the child as were the parents in the Cho and Gannotti investigation.

Unlike Cho and Gannotti (2005), Park et al. (2001), and Salas (2004), however, my participants attributed the perceptions that professionals lacked concern for their parental expertise and their opinions to differentials of Power and Authority rather than to an issue based on cultural or linguistic background. Based on the results of my investigation, my European American parents were not treated any differently from the parents within these studies that Wolfe and Durán (2013) have reviewed.

Wolfe and Durán (2013) also discussed the theme of perceived *negativity* toward *children*. Teams delineated a child's problems through deficit-based framing. This finding is a continuation of issues presented by Thoma et al. (2001). See Chapter I, *On-Going Problems*, for that discussion. Wolfe and Durán discussed perceived negativity toward children when discussing the results of Edwards and DaFonte (2012) and Park et al. (2001). Wolfe and Durán wrote: "The deficit view of disability often presented by

professionals in IEP meetings runs counter to establishing a positive working relationship" (p. 12). This counterproductivity occurs most often when parents "value their child for their unique strengths and talents" (p. 12). Participants in this investigation also were critical of the deficit-based framing of their children, particularly participants who had children that are considered twice exceptional, having classified as having a disability and as being gifted.

As noted earlier in this section, Wolfe and Durán (2013) discussed Lian and Fontanez-Phelan (2001), Hernandez et al. (2008), and Hughes et al. (2002) as outliers to their literature review. They considered these investigations outliers as they had only one or two themes that were shared by others or approached the research differently (Wolfe & Durán, 2013). Barriers to communication and insufficient information were reported by Hughes et al., and Lian and Fontanez-Phelan only found barriers to communication as problematic. All three investigations stated that their participants were happy and satisfied with the IEP process (Wolfe & Durán, 2013). For example, Wolfe and Durán reported that in the investigation by Hughes et al., 82% of participants helped develop goals, 89% believed goals and objectives were family oriented, and 86% felt like an equal member of the team. In a review of the Hughes et al. investigation, I noted that 50% of the children in the study were preschool age, which in my opinion, skewed results. While IEPs for preschool children are "education" centered rather than "family" centered, typical early-childhood preschool program teachers are cognizant of the differences between an IFSP (Birth to 3), and an IEP (3 to 5). As such, it has been my experience that these teachers engage parents more interactively. They allow shared goal development,

provide space for parental opinion within the special education process, and value parental contributions in the classroom.

Additional culturally diverse investigations of parents' perceptions. During my literature search, I found one additional investigation not reported by Wolfe and Durán (2013). Freeman-Nichols (2013) conducted a critical investigation of black parents' participation in special education decision-making. Her qualitative investigation utilized a critical humanism paradigm (Freeman-Nicholas, 2013). This researcher examined the intermingling of sociocultural contexts, process, and experiences of four parent participants that were African American and middle-class (Freeman-Nicholas, 2013). She examined their perceptions and attitudes concerning involvement in the special education process and decision making (Freeman-Nicholas, 2013). Like this investigation, Freeman-Nicholas identified differentials of power between professional and parent with the professional having considerably more decision-making power than parents. Like the results of my investigation, this power differential shaped interactions between parents and professionals throughout the special education process (Freeman-Nicholas, 2013). Also, as in my investigation, this researcher found that district-based structural issues compromised the parents' ability to receive the provisions of a Free and Appropriate Public Education (FAPE) and the least restrictive environment (LRE) for their children with disabilities. Last, as in my investigation, the investigation by Freeman-Nicholas (2013) revealed that parents' interactions with professionals, shaped views of both the parent and the professional.

Survey literature. Five survey studies were found specific to parental

perceptions of the special education process. These studies include investigations by Fish (2008), Kemp (2012), Lundy (2012), Rodriguez and Elbaum (2014), and Simon (2006) (see Table 3).

Two surveys, Fish (2008) and Kemp (2012) had 51 parent participants; two more, Simon (2006) and Lundy (2012) had 143 and 389 parent participants, respectively. The survey by Rodriguez and Elbaum (2014) used existing survey responses from 5689 parents of special education students collected by the State Department of Education in Florida. When combined, these five studies explored parent perceptions across six IEP requirements, perceived human value, relationships between parental stress, SES, and services provided. It also included an understanding of rights, equal treatment, involvement, and engagement in IEP development and services.

Not surprisingly, Simon (2006) found significant differences between parent and teacher perceptions, between educational levels of students, and interactions between groups and educational levels. Fish (2008), however, reported that most of his participants had favorable IEP meeting experiences. They were valued, respected, and an equal decision-maker. In this study, a welcoming atmosphere enhanced comfort. Also, most of his participants had a clear understanding of IEP procedure and law, Results from Fish, however, are likely biased by parent recruitment from a parent advocacy center. Lundy (2012) found no significant differences in perceived stress, disability type, and 'Family Quality of Life.' Satisfaction with services was a near predictor, and parental stress was a predictor of family quality of life. Kemp (2012) found that income, education level of the parent, and a child's disability category were not significant in determining

Table 3

Parent Perceptions of the Special Education Process - Surveys (2006-2017)

Citation	Participants	Purpose and procedure	Relevant findings
Simon (2006)	Teacher sample $(n = 98)$; parent sample $(n = 143)$.	50-item survey used to assess parent perceptions of the IEP requirement. The survey had ten statements related to IEP functioning in five areas: Communication Vehicle, Opportunity for Resolving Differences, Commitment of Resources, Management-Compliance Tool, & Evaluation Device.	Significant main effects based on group affiliation (parent vs. teacher); significant main effect based on associated children's educational level; significant interaction effect based on group affiliation and associated children's educational level.
Fish (2008)	51 parents of students receiving special education services from a family support service agency.	"To determine how parents of children who receive special education services perceive IEP meetings and how they perceive their being valued by educators during the process" (Fish, 2008, p.; 9); Likert scale questions and two open-ended questions.	Most parents reported favorable IEP meeting experiences, including being valued, respected, and equal decision makers to teachers; welcoming atmosphere enhanced comfort levels. Most had a clear understanding of the IEP process and law, likely due to a family service agency.
Lundy (2012)	Parents of children with disabilities ($N = 389$), preschool to 12 years of age ($M = 8.6$, $SD = 2.3$).	Investigated the relationships between parental stress, SES, satisfaction with social services, and Family Quality of Life among parents of children with disabilities within a school setting.	(a) Researchers found no significant differences between parental stress levels and FQOL between the child disability types; (b) Satisfaction with services nearly reached statistical significance in predicting FQOL while parental stress reached significance.
Kemp (2012)	51 parents of children with disabilities.	Parental participation is worthy of investigation given that schools are accountable to make certain that parents understand their rights, are treated as equal partners and are involved in all the aspects of writing the IEP .	Income, Education Level, and Disability Category on the perception of IEP Meeting were nonsignificant; Material Status and Years of Experience with IEPs were significant.
Rodriguez & Elbaum (2014)	Florida State Dept. of Ed. Database of 5689 parents' responses to an annual statewide survey.	Evaluated the contribution of school-level factors to schools' efforts to engage parents of children receiving special education services. Sought to clarify ways in which student-teacher ratio moderates the relationship between other school-level factors and schools' engagement efforts.	School-level features jointly explained almost a quarter of the variability in schools' efforts to engage parents. School size and grade level were not strongly related to schools' parent engagement efforts. Through SES, there was a small, statistically significant effect on perceptions. Parents in lower SES schools perceived stronger engagement than higher SES schools. Student-teacher ratio was the strongest predictor of a schools' efforts.

parent perceptions. Marital status and years of experience with IEPs, however, were significant factors. For parental engagement, Rodriguez and Elbaum (2014) found that school size and grade level) were strongly related to parent engagement efforts within the special education process. SES had a small significant effect on parental perceptions with parents in lower SES schools perceiving stronger engagement. Student-teacher ratio was the best predictor of engagement.

The results of these five studies are mixed. Each investigator looked at perceptions of parents within the context of the special education process from different angles or points of view. These different viewpoints included parent satisfaction, engagement, and participation. Factors that contributed to satisfaction were different in all five studies, indicating justification for further perception research into how parents view the special education process. It also indicates the need for case study exploration due to the inconsistency in results.

Transition literature. I located six investigations related to parent perceptions of the special education process and the process of transition. This research includes work by Salmon and Kinnealey (2007), Hicks (2012), Rugg and Donne (2011), Lee, McCoy, Zucker, and Mathur (2014), Walker et al. (2012), and Cawthon and Caemmerer (2014). Of these six studies, three were mixed methods, one was quantitative, one was a metasynthesis, and one was qualitative. I discuss these studies in turn (see Table 4).

Mixed-methods in transition literature. Hicks (2012), Rugg and Dunne (2011) and Walker et al. (2012) completed mixed method investigations. These researchers investigated different aspects of the parent perceptions and the transition process. Hicks,

Table 4

Parent Perception of Special Education Process Transitions (1997-2017)

Citation	Participants	Purpose and procedure	Relevant findings
Salmon & Kinnealey (2007)	Nine parent-student dyads	To explore the transition experiences of youth with disabilities and their parents as they prepared for life after high school. Qualitative, grounded theory study of parent and student perceptions	Three major themes: transition facilitators, transition constraints, and participant strategies. Both facilitators and constraints filtered into the same minor themes: personal., educational, community, and governmental
Hicks (2012)	60 caregivers of children who transitioned to School- aged services	Investigated caregivers' perceptions of the transition process for children transitioning from Early Childhood to School Age SPED services. 30 caregivers' children received itinerant intervention; 30 received the classroom-based intervention. Mixed methods.	Late placements result in caregiver uncertainty. Many did not see the benefits of or barriers to transitioning. Team membership feelings were mixed. Themes: mixed feelings regarding the process and general uncertainty.
Rugg & Donne(2011)	12 parents of children transitioning from hearing program to general education	To determine parent perceptions of their transitioning students, moving from an LSL school into the general education. To determine students with hearing impairment's degree of preparedness for general education. Mixed methods.	Parents and teachers satisfied with transition process. Components of transitioning include supportive staff, a student presentation program, partial mainstreaming, and transition workshops. Students were prepared and maintained academic progress, but vocabulary development was needed.
Walker et al. (2012)	54 parents of children with developmental disabilities and their teachers	To assess parent and teacher perceptions of the inclusive program placement, satisfaction with the support, and judgments of transition success; to examine how these relate to children's level of disability, approaches to learning, perceptions of appropriate placement. Telephone interviews. Mixed methods.	Found a lack of preparation from schools for a child's physical, developmental needs; teachers challenged by children's needs within the context and resources of the classroom. Parents viewed transitioning as simple more so than teachers. Teachers saw the transition as smooth when they appropriately placed children.
Cawthon & Caemmerer (2014)	56 parents with children who are deaf or hard of hearing	To explore parent postsecondary outcome expectations and perspectives on transition planning for children who are deaf or hard of hearing. Quantitative methods.	Parents had positive experiences with the IEP process. They held high expectations for their child's educational attainment and employment. Differences in expectations and perceptions emerged among parents whose children had co-occurring disabilities.
Lee, McCoy, Zucker, & Mathur (2014)	Meta-synthesis of current literature and research.	To identify and understand trends in the family perception of academic transition issues related to children with ASD to proactively utilize the understanding in future ASD transition planning. Meta-synthesis of current research.	Pre-school teachers support transitioning, elementary staff not as involved; Secondary parents interested in social acclimation, peer acceptance; students' self-esteem and coping skills; Post-secondary: Independence, social skills, work potential, and preparation were top priorities. Individual planning important.

for example, examined parents' perceptions from two groups of children, those receiving pull-out services and those receiving services in the classroom. Hicks found uncertainty in both parent groups when late programming placement became an issue. Many of her parents did not see the benefits of transition services or barriers within the process. Rugg and Donne (2011), however, investigated parents of children who were deaf or hearing impaired. These researchers found that parents were satisfied with the transition process. A supportive staff, a student presentation program, partial mainstreaming, and transition workshops contributed to that satisfaction. Last, Walker et al. (2012) examined parent and teacher perceptions of inclusive placement, satisfaction with support, and judgments of transition success. These investigators found a perceived lack of preparation from schools for a child's physical needs. Teachers, on the other hand, were challenged by the children's needs within the constraints of their existing resources. Interestingly, parents viewed the transition as effortless when compared to teachers. But teachers saw the transition as smooth when they placed the child successfully and appropriately.

Quantitative methods in transition literature. Cawthon and Caemmerer (2014) conducted a quantitative investigation of parent post-secondary outcome expectations and perspectives on transition planning for children who were deaf or hard of hearing. Like Rugg and Donne (2011), Cawthon and Caemmerer found that their parents had positive experiences with the IEP transition process. Parents also generally held high expectations for educational attainment and employment; however, if the children with disabilities had co-occurring disabilities, expectations on attainment and employment were lower.

Meta-synthesis in transition literature. Lee, McCoy, Zucker, and Mathur (2014)

completed a meta-synthesis of autism spectrum disorder (ASD) and transition literature. They intended to discover trends in the family perception of academic transition issues related to children with ASD. When looking at preschool transition programs, Lee et al. found that preschool teachers support the transition process, but support from elementary staff is lacking. For secondary transitions, she found that parents are interested in social acclimation, peer acceptance, students' self-esteem, and coping skills. As will be discussed in chapters four (survey results), and chapter five (main themes), my parent participants expressed these same needs for their children with disabilities, regardless of disability type. Lee et al. also found that for parents with children encountering post-secondary transition, the needs were independence, social skills, work potential, and preparation. Again, Lee et al.'s results are reflective of the results of this investigation.

Qualitative research in transition literature. The research by Salmon and Kinnealey (2007) was the only investigation found that was qualitative and based on grounded theory. Salmon and Kinnealey looked at the dyad between parent and child responses to transition experiences. The investigators uncovered three themes: transition facilitators, transition constraints, and participant strategies. Both facilitators of transition and constraints of transition filtered in the same minor themes which included personal facilitators and constraints, educational facilitators and constraints, community facilitators and constraints, and governmental facilitators and constraints.

Membership literature. One investigation, Scorgie (2015), was located that investigated parents' perceptions of membership (i.e., views of membership within the special education team, the child's classroom, school, and community) for themselves

and their children with disabilities. Related to membership is a concept Scorgie identified as *boundary ambiguity* as she discussed Boss (2002, 2004, 2007), the "confusion over the structure of or functioning within a group" (p. 40). Scorgie (2014) noted that this confusion or boundary ambiguity could occur within the home-school context as Scorgie referred to Boss (2002, 2004, 2007). Boundary ambiguity confusion can also transpire through an individual's perception of membership or role (Scorgie, 2015, p. 40, citing Carroll, Olson, & Buckmille, 2007).

In discussing membership ambiguity, Scorgie (2015) reviewed relevant codes and themes that build this concept. For a child with disabilities, for example, membership ambiguity can reveal itself through labeling, segregation, differential treatment from teachers or peers, and *inconsistent support* from school community members (teachers) (Scorgie, 2015, p. 41). As such, being *labeled* can stigmatize. If a child feels different, there can be academic and social implications (Scorgie, 2015); likewise, isolation can occur through segregation from self-contained classroom placement: that is, these children do not experience shared school activities (Scorgie, 2015. As Scorgie points out, even in inclusive classrooms, a labeled child can feel isolated from his or her peers. Scorgie further noted that "segregation in school may result in acceptance of segregation in adulthood" (p. 41). As noted, Scorgie also stated that membership ambiguity could reveal itself through differential treatment from teachers which can affect a child's selfesteem and academic performance. And last, if membership ambiguity reveals itself through inconsistent community support, then parents begin "to question [the] child's value within [the] community" (Scorgie, 2015, p. 41).

For a parent, membership ambiguity can reveal itself through *condescending treatment* from professionals, *labeling*, and *resource allotment* (Scorgie, 2015, p. 41). As such a parent who experiences disdain by professionals may feel "devalued and overlooked" (Scorgie, 2015, p. 41); Scorgie also noted that parents might be *labeled* by professionals when there is disagreement. Parents become "difficult, unrealistic, and uncooperative" (p. 41); or professionals view parents as "takers" but "not contributors" to the system. This devaluation creates ambiguity from differing opinions about resource allotment (Scorgie, 2015, p. 41).

Concerning *Role Ambiguity*, parents may perceive themselves as "gatherers of information" or parents may feel that professionals conceal information or that they are uninformed (Scorgie, 2015, p. 41). Relatedly, Scorgie noted that parents might need to "become educators of teachers" (p. 41), meaning that with *information*, parents may perceive themselves as having *Power*. The second aspect of *Role Ambiguity* described by Scorgie is *Advocacy*. Specifically, when parents must advocate for their children, it is "time-consuming, ongoing, and exhausting" process (Scorgie, 2015, p. 41). Moreover, Scorgie noted that when legal action is required, parents must take on an adversarial role. The third aspect of *Role Ambiguity* concerns homework amounts and the parents' ability to support the child with homework tasks. Scorgie noted that "poorly completed homework reinforced teacher perception of parent as uninvolved/uninterested" (p. 41).

Rural district literature. One qualitative investigation, Lehman (2009), was discovered during the literature review process that examined parent perspective of the special education process within the context of rural settings. While "rural" is not the

focus of this qualitative investigation, it is important as it was within a rural district that the seed of this investigation took hold and it is where I gathered pilot data. Moreover, 1 participant in this investigation identified themselves as living in a 'rural' area, not a farm or ranch, and five additional participants indicated that they resided in a small town.

Additionally, the sample size was equivalent. As such, this one investigation holds relevance for review.

Lehman (2009) identified factors that affect rural parents and spill over into the special education process. A primary issue is that many families are of lower SES (Lehman, 2009). Nationally, as of 2015, 59% of rural districts received Title 1 funding (U.S. Dept. of Education, Office of Elementary and Secondary Education, Office of State Support 2015). In the rural district where I began to consider and conceive this investigation, between 2006 and 2013, 85-88% of the school districts' families received free or reduced lunch, indicating the level of poverty and need within that district.

A second challenge of providing special education identified by Lehman (2009) for rural districts was the "entire IEP process, itself" (p. 39). Lehman discussed O'Dell and Schaefer (2005) who had conducted interviews of rural school district IEP team members; these investigators identified a lack of highly-qualified teachers as the primary concern. Lehman noted through this research that a lack of high-qualified teachers leads to a "lack of expertise and understanding by staff on what needed to be done to stay within legal compliance of IDEA" (p. 40).

In her results, Lehman (2009) identified one primary parent role and two themes.

For *parent role*, Lehman discussed the role of advocate. This finding aligns with my

results. For themes, Lehman reported that the theme *Trust* emerged when parents within rural communities perceived that the school district had honored their feelings, when a collaborative atmosphere was present, and when the parents perceived themselves as equal partners within the special education process. The theme *Disenfranchisement*, however, was present when parents within rural communities perceived that they had been marginalized or felt overwhelmed (Lehman, 2009). Lehman noted that above all, however, the "biggest single object of displeasure [for parents in rural communities] involved comments which focused on the excessive amount of paperwork that seemed to be a hallmark of the entire process" (p. 64). With that, Lehman noted the value system of her participants was at odds with the IEP requirement. Participant 4 of Lehman's investigation stated the following about the IEP process.

I see it (the meeting) as a reason to have a big group of people to all sit down and try to accomplish what I see is nothing. It's of no benefit to the people who are there, and it's no benefit to my son. It's about paperwork, and bureaucracy an illusion for the parent to show that something is getting done when there really is nothing. There is so much more that the school system could do to help my son. (p. 64)

Categorical literature. I located twelve investigations that examined the special education process through the lens of parent perceptions concerning a child's category of disability (see Table 5). Parent perceptions surrounding Autism was the most abundant category found in the literature. These investigations include Lautenbacher (2014); Tucker and Schwartz (2013), Baghdayan (2012), and Fish (2006). Broomhead (2013) examined parent perceptions, behavior, and special education. Duquette, Orders, Fullarton, and Robertson-Grewal (2011) and McCulloch (2010) researched parent perceptions and gifted education. For intellectual disability, Leyser and Kirk (2011)

Table 5

Parent Perceptions of Special Education Processes: Disability Type

Category	Author and year	Subject of inquiry
Autism	Lautenbacher (2014)	Building Bridges: A Case study of the perceptions of parents of students with autism spectrum disorder (ASD) towards family/school partnerships
	Tucker & Schwartz (2013)	Parents' Perspectives of Collaboration with School Professionals: Barriers and Facilitators to Successful Partnerships in Planning for Students with ASD
	Baghdayan (2012)	A Study on Parents' and Educators' Perception on Including Young Children with High-Functioning Autism in General Education Settings
	Fish (2006)	Perceptions of Parents of Students with Autism towards the IEP Meeting: A Case Study of One Family Support Group Chapter
Behavior	Broomhead (2013)	Preferential treatment or unwanted in mainstream schools? The perceptions of parents and teachers with regards to pupils with special educational needs and challenging behavior
Gifted	Duquette et al. (2011)	Fighting for their rights: Advocacy experiences of parents of children identified with intellectual giftedness
	McCulloch (2010)	How Stakeholders Perceive Gifted Education: A Study of Beliefs Held by Stakeholders in Elementary Gifted Education Programs
Intellectual disability	Leyser & Kirk (2011)	Parents' Perspectives on Inclusion and Schooling of Students with Angelman Syndrome: Suggestions for Educators
Multiple disabilities	Ryndak et al. (1996, 2011)	A Mother's Perceptions of Her Ongoing Advocacy Efforts for Her Son with Significant Disabilities: Her Twelve-Year Journey. Parents' perceptions of educational settings and services for children with moderate or severe disabilities

provide an investigation of parent perceptions. Last, for perceptions of special education and children with multiple disabilities, Ryndak, Downing, Morrison, and Williams (1996) and Ryndak, Orlando, Storch, Denney, and Huffman (2011) provide investigative work. I review these works in the five sections that follow.

Autism. The investigations by Lautenbacher (2014), Tucker and Schwartz (2013), and Baghdayan (2012) provide tangentially related information to this research project. These investigators studied parent perceptions of parents who have children with Autism. Lautenbacher (2014) examined parent perceptions of partnerships between parents of children with Autism and educators, Tucker and Schwartz investigated collaboration, while Baghdayan examined parent and educators' perceptions of children with highfunctioning autism relating to inclusive settings. From all three studies, however, one can glean that parent-educator partnerships or parent-educator collaboration is crucial to the success of a child with a disability such as Autism. Baghdayan, for example, noted that the primary source of parent concern was related to lack of support and appropriate services. Baghdayan also noted that parents perceived the practice of inclusion to create a canvas for collaboration; parents perceived themselves as partners rather than threats with educational professionals. Parents and professionals worked on common goals and resulted in children's success in school (Baghdayan, 2012). Moreover, "collaboration was the most effective when it was focused on interactive teamwork across families and their schools" (Baghdayan, 2012, p. 145), benefiting school practices and students (Baghdayan, 2012). Lautenbacher found that parents were motivated toward partnership by Invitations for Involvement when there were offers of friendship, communication, an

open-door policy, and acts of kindness. In Lautenbacher's (2014) study, trust motivated parents toward partnership. Trust developed from follow-through, student support, and by Understanding and Accommodating. Lautenbacher (2014) identified Barriers to Involvement which included Lack of understanding, Emotional disconnect, and Judgement. These themes by Lautenbacher (2014) are highly reflective of this current investigation. Through survey research, Tucker and Schwartz described parents who were "willing to be involved in their child's educational program but found it difficult to do so because of their perceived barriers constructed by the school district" (p. 10). These barriers included lack of communication, disagreements regarding student placement, programming, and services provided to students. In their investigation, Tucker and Schwartz noted that increasing communication opportunities, having access to information, and valuing parental input would improve the collaborative experience. Last, Tucker and Schwartz provided additional impetus for my investigation; these researchers noted that "special educators must develop a deeper understanding of parents' perspectives so that teams and leaders can use this information to be proactive" (p. 10-11).

Fish (2006) examined qualitatively the perceptions of parents who have children with Autism concerning the special education process. Fish demonstrated that parents of students with autism did feel as if they were equals at IEP meetings. Fish further reported that these parents believed that their input was not of value or welcomed during these special education meeting exchanges; they sought to be equal contributors at these meetings. The parents in Fish's investigation also discussed their belief that IEP goals

and objectives were not fully implemented and as such desired adherence to the plan outlined in the meeting so that their children could benefit from their special education services. Last, parents within Fish (2006) perceived that districts weren't doing enough to educate them about special education law. As such, parents taught themselves and utilized this knowledge to acquire appropriate services for their children with Autism.

Behavior. Broomhead (2013) examined the perceptions of parents and teachers regarding students with disabilities and challenging behavior. In her investigation, Broomhead highlights differing perceptions. Supporting previous literature (Farrell & Polat, 2003; Jull, 2008; O'Connor, Hodkinson, Burton, & Torstensson, 2011; Russell, 2008), Broomhead found "organizational exclusion" toward children with disabilities who display challenging behavior. In discussing Orsati and Causton-Theoharis (2013), Broomhead noted that her findings were like these investigators who reported that "teachers excluded pupils who they perceived as challenging, in order to preserve control in the classroom" (p. 8). At the same time, however, the professionals Broomhead interviewed did not indicate that children with disabilities who display challenging behavior were 'unwanted.' As such, two primary themes emerged from the five parents of children with behavioral, emotional, and sensory challenges that Broomhead interviewed. Broomhead noted that parents "talked intensely" as to how their children were "unwanted" (p. 5) while professionals differed in this opinion. Broomhead also stated that some parents discussed how their children needed "preferential treatment" in the school and classroom. Other parents, however, opposed "preferential treatment" for children (pp. 6-7).

Gifted. During the data collection phase of this investigation, I interviewed several parents who had children considered "twice exceptional" (gifted and/or talented plus a disability). As such, I felt it was important to review parent perceptions related to gifted education and the special education process. That is, children who are gifted go through the same or a highly similar process to children requiring specialized instruction. The children are identified, referred, and evaluated. An eligibility meeting follows this evaluation. If the team concludes that the child qualifies as Gifted, then the team proceeds to develop an IEP to meet those gifted needs. As such, children considered twice exceptional will have an IEP for both needs at both ends of the spectrum.

Duquette et al. (2011) and McCulloch (2010) examined perceptions of parents with gifted children relating to the special education process. Duquette et al. focused on parent experiences specific to four dimensions of advocacy—awareness, information seeking, making the case, and monitoring (Grantham, Frasier, Roberts, & Bridges, 2005). Duquette et al. found that

...like parents of children with disabilities, these participants were primarily focused on meeting the needs of their children. When they exercised their right to be involved in the process of decision making for their children, many parents faced opposition...particularly on the issues of identification of giftedness, placement, and accommodations for children with a dual diagnosis. (p. 504)

When this occurred, parents responded through advocacy for their children much as the 14 parents of children in my investigation engaged in advocacy when interacting with special education team professionals.

McCulloch (2010), through quantitative analysis of survey research, demonstrated that many areas exist where district stakeholders in gifted education share similar beliefs

to parents of gifted children. According to McCulloch, the research literature substantiated most of these beliefs. McCulloch also found, however, quantifiable differences in beliefs of stakeholders which could be potential sources of tension during identification and IEP meetings. McCulloch examined beliefs around curriculum, resources, and equity.

For curriculum beliefs, McCulloch (2010) reported that most administrators believe grade-level textbooks are appropriate for students who are gifted, while all other stakeholder groups do not believe that to be the case. McCulloch also demonstrated that parents and teachers support, for the most part, pullout programs. Administrators and experts in gifted education view pullout programs as too insufficient for meeting these children's needs. Likewise, parents and teachers believe acceleration to higher grades is appropriate, while most administrators disbelieve in grade advancement. All group in McCulloch's investigation, however, strongly supported differentiation for children with gifted needs.

Concerning resources, McCulloch (2010) demonstrated that there was agreement between all stakeholders that public-school districts should support gifted education as general education teachers are not adequately trained to meet the needs these children possess. Underrepresentation of culturally diverse students was a belief supported by all groups investigated regarding gifted education.

For equity, McCulloch (2010) reported that her stakeholder groups believed that gifted education programs could benefit all students. McCulloch also stated, however, that parents differed from administrators and educators on the issue of identification; with

parents believing their children would not receive appropriate support without being formally identified. Last, McCulloch stated that parent perceptions diverged as to whether the proper identification of culturally diverse and economically disadvantaged students was even possible. Administrators, on the other hand, believed current practices appropriately identify these students.

Intellectual disability. Leyser and Kirk (2011) examined quantitatively and qualitatively the perceptions of parents who have children with Angelman's syndrome, a severe and complex disability. These investigators examined inclusion and special education through survey research that involved 68 parents from across the U.S. The individuals within their investigation responded to a scaled survey and several openended questions.

The themes uncovered by Leyser and Kirk (2011) echo the themes from the other identified categorical literature. In their investigation, relationships with schools or districts and poor communication remains a central, recurring theme for parents that left them dissatisfied (e.g., "district communication has been horrible since day one. District attentiveness to my daughter's needs has been negligent at best," p. 85). And as in my findings, parents within Leyser and Kirk (2011) expressed a variety of quality of life concerns that were not unlike those expressed by my parents. That is, they desired that their child develop "social skills, a social life, and friends" (p. 85), be happy and enjoy life, as well as be "independent as possible…and be able to communicate" (p. 86).

The parents within the Leyser and Kirk (2011) investigation also revealed what they wanted educators and administrators to know about their children through a theme

of value and worth; specifically, the child is more than his or her diagnosis. With that, Leyser and Kirk provided many examples of parent responses surrounding this theme, including: "do not underestimate, he/she can learn...is capable, more than the school realizes; has gifts; they are smart" (p. 86). These comments are not unlike the comments from my participants who express the need to feel valued during special education process discussions for themselves and their children with disabilities.

Last, Leyser and Kirk (2011) described value reflective sentiments from their participants that mirrored my participant's discourses. Surrounding the concept *expertise*, these statements included, "we are not the experts; we are parents" (p. 86). Surrounding the concept *seeking support*, these statements included, "We want you to help us to help our children" (p. 86). For the desire to *not be judged*, these statements included, "our life is hard, and they should not judge us" (p.86). And for the concept, *advocacy*, these statements included, "we will do whatever we need to do to help him and give him the best life possible" (p. 86).

Multiple disabilities. Ryndak et al. (1996, 2011) discussed perceptions of the special education process through the lens of parents who have children with multiple disabilities. In the earlier investigation, Ryndak et al. (1996) investigated parent perceptions of inclusive settings and special education processes for children with multiple disabilities. These investigators reported several participants who commented on feeling powerlessness, specifically when regarding service location and their child's right to F.A.P.E. In their discussion—and not unlike the participants in my investigation—Ryndak et al. (1996) highlighted how parents in their study felt devalued.

Parents had clear ideas about what constituted appropriateness versus inappropriateness and least restrictive versus more restrictive in relation to the location of services and instructional content. The overall unhappiness and frustration that parents expressed about the process used to decide the location in which their child would receive services suggest that parents are not valued members of their child's education team, or that school districts are not sufficiently open to discussing the pros and cons of services in various types of settings. Once their child started to receive services in general education settings, discussions about the type of setting for future services ceased. (p. 116)

Parents in Ryndak et al. (1996) also expressed "anger and amazement...about their district's lack of understanding of their child's need for a natural support network and the ensuing need for opportunities to interact with same-age peers without disabilities...." (p. 116). This sentiment emerged from several parents who had children with more severe needs in my investigation.

Last, in the investigation by Ryndak et al. (1996), as in my own, the theme of being valued or worth was expressed by his participants. They valued opportunities to give team members input about the instructional content they considered appropriate for their child. As Ryndak et al. stated:

When this input was accepted, parents felt that it resulted in an IEP and educational program that was truly individualized to meet what they perceived to be their child's most immediate needs in the real world, while capitalizing on their child's strengths. The importance of being able to recognize and build on student strengths versus focusing on deficits to establish curricular content was stressed by several parents. (p. 116)

In the more recent investigation by Ryndak et al. (2011), these investigators examined a single mother's perceptions regarding her son who has multiple disabilities. The authors investigate the mother's advocacy efforts across a 12-year span of time.

Ryndak et al. (2011) reported that two themes emerged during this investigation.

The first concerned her son's educational services, the educational setting, and the

decision-making process used to select those services and settings. Ryndak et al. stated that there was "the perception of congruence or conflict between" the mother's views of her son and that of "the educational service providers' views" of her child (p. 79). According to Ryndak et al., there was "a cycle of hope, frustration, despair, information gathering, and decision-making all of which were based on [the mother's] perceptions of congruence or conflict between her view and the views of educational service providers" (p. 79). I noted this cycle in my participants who had children with more significant needs.

The second theme discussed by Ryndak et al. (2011) was family stress during transitions from service provider agencies and during transitions between schools. These researchers describe how the parent in their investigation had a "goodness of fit" conflict (p. 86). That is, she enjoyed her son's early intervention services but was conflicted by the educational services of the school district. Ryndak et al. stated that the child's "school-age service providers led her to believe that nothing she said or did short of threatening to use her right to due process would change their views of her son" (p. 86). Moreover, Ryndak et al. stated that the mother believed that

...school personnel perceived their services as adequate and appropriate regardless of whether those services met her son's needs. She believed, therefore, that nothing she said or did would help the school personnel accept the thought that their services should change to meet her son's needs. (p. 86)

This thought, expressed by the parent in Ryndak et al. (2011), reflects the perceptions of several of my participants who described how the district lacked knowledge about their child's condition and refused to offer effective support and services to meet the child's needs.

Thematic Literature

In the following sections, I present literature on the themes uncovered during this investigation. Specifically, I discuss dignity, equity and equality change literature, advocacy, as well as "voice" literature as I want the reader to begin thinking about the models of disability presented earlier in this chapter and the specific themes that emerge from the discourse of my participants. From the equity and equality literature, for example, I refer to Kozleski and Smith (2009) in Chapters V and VII as the model they present (discussed below) that suggests a path forward. Likewise, from the voice literature in Chapters V and VII, I refer to MacLeod, Causton, Radel, and Radel (2017) who present research that connects to the models of disability.

Dignity literature. Dignity, at its most basic level, is an elementary need of humankind. The United Nations, for instance, has stated that all individuals are equal in dignity. All individuals are also entitled to human and civil rights (United Nations, n.d.). Pennington, Courtade, Jones Ault, and Delano (2016) argued, however, that this vision has been lacking with children who have moderate to severe intellectual disabilities. Pennington et al. reported that the literature is full of cases of these individuals being mistreated or abused, isolated or segregated, living in squalor, and the object of discrimination (Griffiths et al., 2003; Horner-Johnson & Drum, 2006; Ward & Stewart, 2008). Because of this literature, Pennington et al. discussed a position statement from the American Association on Intellectual and Developmental Disabilities (AAIDD, 2009). It reads, "The human and civil rights of all people with intellectual and/or developmental disabilities must be honored protected, communicated, enforced, and thus

be central to all advocacy on their behalf" (para. 1).

Despite this position statement, there is only mixed evidence that situations for children with moderate to severe disabilities are improving. For example, on the contrary side, Westling, Trader, Smith, and Marshall, (2010) reported that

Students with disabilities, who are most often between the ages of six and ten years with Autism Spectrum Disorders (ASD) or behavioral disorders, are often being restrained and/or secluded in response to their behavior. Sometimes, they are also subjected to other aversive procedures such as being slapped or pinched or having food withheld. The data indicate that the actions usually occur in a special education classroom between 1 and 10 times per year per student. (p. 125)

The data of Westling et al. (2010) also demonstrated that these students were subject to restraint holds and seclusion in an area from which they could not escape. This restraint or seclusion typically lasted from five to thirty minutes, but sometimes longer—up to several hours. Last, Westling et al. (2010) reported that administrators and school personnel at all levels of training were complicit in these actions. These researchers also stated that behavior interventions were scarce and they noted a reporting failure, writing the "school does not report to the parent or guardian that restraint, seclusion, or an aversive procedure has been used" (p. 125).

Through the scholarship of Griggs et al. (2011) and Hayden and Pike (2005), Hodge (2015) reported positively that many schools are responding to "the challenge of behavior through an embracement of approaches that include positive handling" (p. 194). Regarding *dignity*, however, Pennington et al. (2016) wrote:

Schools must provide environments in which students are treated with dignity. In interactions with students, administrators should observe that professionals maintain calm demeanors, and use tones of voice and facial expressions that are free of sarcasm or ridicule. Professionals should refrain from speaking in front of students as if they are not present, or speaking about confidential or private topics

concerning the student in the presence of others who may overhear. The privacy of students must be protected especially when students require assistance with personal care needs. (p. 296)

Advocacy literature. Power differentials exist between parents and schools (Leiter & Krauss, 2004). This differential has led to disempowerment and weakened partnerships between the school and family (Leiter & Krauss, 2004). Similarly, Kalyanpur, Harry, and Skrtic (2000) wrote that parents feel that lack legitimacy as they are not an "expert;" this lack of legitimacy led to unequal partnerships. Likewise, recent research by Rodriguez, Blatz, and Elbaum (2013) showed that some Latino parents feel disempowered by lack of knowledge regarding their special education rights. That is, miscommunication or poor knowledge transfer can also occur due to inadequate translation during special education process meetings or be due to literacy issues as the Special Education Procedural Safeguards (Parent Rights Booklet) is typically written at a sixth-grade level (Mandic, Rudd, Hehir, & Acevedo-Garcia, 2010).

Burke (2017) discussed the work of Jones and Prinz (2005), noting that "when parents have greater empowerment, they respond to challenges with optimism, leading to improved child outcomes" (p. 57). While discussing Gutierrez (1990) and Koren, Dechillo, and Friesen (1992), Burke reported that "empowerment can occur at three levels: (a) family (i.e., parent management of daily situations), (b) service delivery system (i.e., services that the school provides), and (c) community/political (i.e., policies that impact families)" (p. 57).

Equity and equality change literature. Sun (2014) discussed the concepts of equity and equality. Sun stated that these concepts are two strategies one can employ to

produce fairness: that is, when equity occurs, everyone has what they need to be successful; equality, on the other hand, is the act of treating everyone the same. Equality aims to promote fairness; it cannot occur, however, if not everyone starts at the same place or needs the same help. On the surface, equity seems unfair, however, by employing equity everyone moves closer to success by receiving an equal opportunity. The challenge with equity is that "not everyone starts at the same place, and not everyone has the same needs" (Sun, 2014). In thinking about Sun's statement regarding children with disabilities, the historical context of special education, and the documented ongoing challenges for children with disabilities, one begins to realize the complexities behind this task. Kozleski and Smith (2009) investigate these complexities. These researchers examined improvement in an urban school through initiatives of an educational equity policy: they refer to Ferguson, Kozleski, and Smith (2003) and Shanklin et al. (2003) who illustrate a "Systemic Change Framework" (Kozleski & Smith, 2009, see also Figure 3), which visually depicts the complexities of equitable change. Kozleski and Smith stated that the framework illustrates "varying levels of effort that combine to affect student achievement and learning in urban schools" (p. 433). Because their focus was inclusive education, Kozleski and Smith noted that

...the framework is designed to bring together the work of practitioners into a unified system of teaching and learning in which the learning contexts for students are organized in ways that engage the students at the margins such as those with disabilities as well as those in the mainstream. (pp. 433-434)

Through the National Institute for Urban School Improvement (NIUSI) under Grant # H326B060012 awarded by the U.S. Department of Education, Office of Special Education Programs (U.S. Department of Education, 2014). Kozleski and Smith (2009)

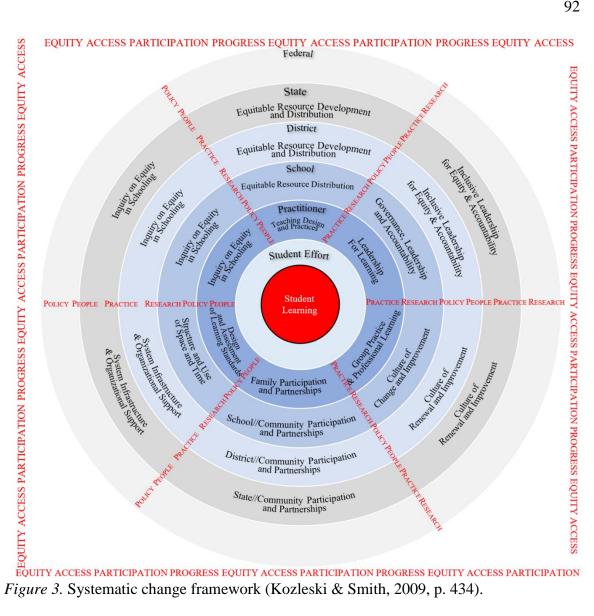


Figure 3. Systematic change framework (Kozleski & Smith, 2009, p. 434).

sought to reduce "the number of students inappropriately placed in special education and enhance general education curricular frameworks and assessments so that learning can be individualized within the context of classroom communities" (p. 434).

The goal within NIUSI, according to Kozleski and Smith (2009), was to begin "with a unified framework to reduce the boundaries that are often observed between the work of special and general educators" (p. 434). Kozleski and Smith noted that the

framework forges a "common language among school professionals whose specialization often creates barriers to common interests" (p. 434). Kozleski and Smith also asserted that because the elements within this *Systemic Change Framework* delineate practices for teaching "students with and without disabilities, schools can integrate inclusionary practices with other reform goals to form a coherent approach to change and renew educational processes" (pp. 434-435).

For readability, I have broken this model down into parts: First, the outcome of the model is *student learning*. It is the bullseye, target, or smallest circle: it is what the federal government, individual states and districts, schools, and practitioners hope to accomplish. In discussing Artiles and Dyson (2005), Kozleski, and Smith (2009) stated that student learning is at "the intersections of structure, sociology, and economics within systems" (p. 429). They also noted that within a system, the participant, culture, and outcomes dimensions required analysis. These authors noted that "because of the interplay between power differentials and regulative functions, community cultures fluctuate between friction and cohesion" (p. 429).

Moving just outside of the center circle is *student effort*. In discussing Sternberg (2007), Kozleski and Smith (2009) expressed that "students expend effort as they seek to make meaning of schooling experiences. This effort recognizes the dynamic nature of learning as a cultural practice that is inhibited or accelerated by individual and institutional responses" (p. 435).

The next largest ring to be identified is *practitioners*. Kozleski and Smith (2009) asserted that "how learning environments are established and maintained rests on the

technical and relational skills, intellectual creativity and curiosity, and cultural perspectives of teachers and other practitioners" (pp. 435-436). As such, this layer directly affects the effort and learning of students (Kozleski & Smith, 2009). Five elements shape the practitioner ring: "(a) learning standards, (b) teaching design and practices, (c) family participation in teaching and learning, (d) group practice, and (e) learning assessment" (p. 436). Importantly, Kozleski and Smith noted that it is the negotiated daily "interplay among students, families, and practitioners" (p. 436) that occurs which creates the dynamic we know as a classroom.

Beyond the *practitioner* ring is the *school* ring. The school-level ring affects all that is below it (practitioner level and student level) but is also affected by district, state, and federal policy (Kozleski & Smith, 2009). Six dimensions define this level: "(a) governance and leadership, (b) structure and use of time, (c) resource development and allocation, (d) school/community relations, (e) culture of change and improvement, and (f) physical environment and facilities" (Kozleski & Smith, 2009, p. 436). While schools are affected from what occurs above and below, Kozleski and Smith pressed that schools "also influence these other arenas by the ways in which administrators connect practitioners, reach out to families, use and distribute resources, and structure time, meetings, and agendas" (p. 436).

For the last layers of the model and to summarize, Kozleski and Smith (2009) wrote:

The next level identifies the systemic elements at the district level. At this level, seven elements emerge, and each of these is conceived as important to the district's efforts for supporting what schools do: student services, inquiry on schools and schooling, organizational supports, resource development and

allocation, systemic infrastructure, culture of renewal and improvement, and district/community partnerships. State law, regulation, and technical assistance shape the work of school systems as does the education policies of the U.S. Department of Education. (p. 436)

To conclude, solutions to achieving equity are complex and dynamic; assumptions that surround theoretical and epistemological assumptions complicate matters (Apple, 1996). With 20 separate factors to consider, not surprisingly, Kozleski and Smith (2009) in discussing Artiles and Dyson (2005) stated that effective "change involves making strategic choices about levels of change that have a high probability of improving the critical products or outcomes" (p. 447). If reform, then, is to be systemic, it will require thinking and design that is systemic as well (Artiles & Dyson, 2005, as cited by Kozleski & Smith, 2009). At the same time, to be effective reform, processes need to be in place "that are designed to mitigate social reproduction, explore cultural historical perspectives, and encourage participant agency in activity systems such as classrooms and schools to produce equitable outcomes for students and families" (Artiles & Dyson, 2005, as cited by Kozleski & Smith, 2009, p. 447).

Voice literature. The last literature I review concerns the concept, voice. Briefly, I want the reader to consider an absence of voice within him or herself. How might that feel? When I use the term voice, I refer to the sense of identity within an individual. It is the ability to express a personal point of view. Voice affords an individual to engage and respond to others, a topic, or a discussion. It enables a sense of belonging and well-being. Voice, then, in the context of this dissertation, is having an acknowledged place within the special education process: the ability to be heard.

Kaczkowski (2013) reported the absence of voice during the special education

process for children with disabilities. Garriott, Wandry, and Snyder (2001); Hauser-Cram, Warfield, Shonkoff, and Krauss (2001); Mueller (2009); Salembier and Furney (1997); and Sauer and Kasa (2012), on the other hand, report absence of voice for parents of children with disabilities. Most recently, the researchers, MacLeod et al. (2017) reported that "parents continue to feel like outsiders" (p. 382; see also Table 6). MacLeod et al. wrote that some research for this perception includes the notion that "teachers continue to feel underprepared to understand diversity as it pertains to families with students with disabilities" (p. 382, citing Hansuvadha, 2009; and Houtenville and Conway, 2008). J. Kim (2013); K. Kim, Lee, and Morningstar (2007), and Stanley (2013) supported this view. Kim and Kim et al. reported that Korean-American parents held attitudes about professionals that became obstacles in meetings. Kim et al. stated:

For example, Kelly's mother lamented that she could not ask for what she wanted and had to follow what professionals suggested, although she actually did not agree to it. Similarly, Brian's mother put more weight on professionals' opinions than her own. Rachael and Grace's father tried to bear harsh comments from some teachers about their child's disability by thinking of a common belief in Korea that a parent who had a troubled child was a sinner. Among five of the Korean American parents, three parents attributed their passive role due to language barriers. These parents noted that the language barrier caused them to frequently avoid participating in school meetings or conferences related to transition planning although they wanted to. Betty's mother confessed that when she had lived in New Jersey, she avoided school activities and meetings unless they were required. When they participated in the meetings, she gave up asking what she wanted to know or following up after the meetings, and she was afraid that she might answer incorrectly. Sometimes, she brought her older daughter as an interpreter to the meeting. Kelly's mother, who had the same experiences as Betty's mother, wished a school transition workshop would be provided in Korean. (p. 259)

Stanley (2013), on the other hand, reported the African-American, participant mothers in her study who voiced their "intuitive advocacy" (knowing their child best)

Table 6

Voice Literature Surrounding Parent Perceptions of the Special Education Process

Citation	Participants	Purpose and procedure	Relevant findings
Kaczkowski. (2013)	Students (<i>n</i> = 7), grades 9–12, placed in a self-contained program for students with emotional disabilities	To determine how the voice of the student was present in the IEP process, documentation, curricular, and diagnostic decisions. Online student survey, document review, and a student-created collage to represent the student's voice in the IEP process. Utilized self-determination theory.	Student survey responses and document analysis demonstrated students were not involved with nor included in planning for or preparing the IEP document
Salembier & Furney (1997)	36 parents of students with disabilities	Examined parent's perceptions of participation in their child's final IEP meeting, 6 to 12 months post-graduation.	Most reported they participated and were satisfied with their participation.
Garriott et al. (2001)	84 parents of students with disabilities	To help educators understand, from the parent perspective, flaws inherent in the current system and ways to legitimize and validate parental participation in the process. The study used a questionnaire with a Likert scale and open-ended inquiries to determine perceived levels of involvement and satisfaction in the IEP planning conference.	89% indicated they "always" attended IEP meetings; most reported no control over meeting schedules; 45% perceived being an equal team member. 27% indicated they "usually" were treated as equal team members; 26% were not satisfied with their level of involvement in their child's IEP conference for a variety of reasons
Hauser-Cram et al. (2001)	Parents of 183 children with disabilities Recruited at time of enrollment in an early intervention program in MA or NH.	Tested conceptual models of child and family development. Staff members were blind to hypotheses. During home visits, one staff member conducted an evaluation of the child, including a standard developmental assessment, an observational assessment of mastery motivation, and an observational assessment of mother-child interaction. A second staff member interviewed the mother.	Using hierarchical linear modeling, the child's disability predicted trajectories of development in cognition, social, and daily living skills. The child's disability also predicted changes in maternal child-related and parent-related stress. Self-regulation and family climate predicted change in child outcomes and parent well-being.
Mueller (2009)	Case study	Examination of an alternative dispute resolution strategy—a facilitated IEP meeting	The facilitated IEP lasted 2 hours. Solution mutually agreed on. Decisions were amicable and team problem solved.
Sauer & Kasa (2012)	Preservice Teachers, 98 families, 125 interviews	A teacher education program engaged families with children with disabilities and preservice teachers to develop more reflective, critical teachers. Two-hour interviews. Preservice teachers actively listened, used paraphrasing, follow-up questions, and followed the family lead.	During the educational experience, preservice teachers repeatedly used language showing the tension most families experience when trying to work with schools. It notes that preservice teachers came out as critical thinkers in the understanding of students with disabilities.
MacLeod et al. (2017)	35 parents of children with disabilities	To explore the experiences, needs, and desires of families of school-aged individuals with disabilities surrounding collaboration of the IEP process. Phenomenological, qualitative approach.	Parent concerns about collaborating with educators included fear and anxiety due to lack of communication, trust, and negative perceptions of disability. Parents perceived partnership with a strengths-based lens, with explanation of ideas and policies. When educators were flexible and willing to learn and try new things, parents collaborated.

during the special education process, did not always obtain "positive outcomes for the mothers and their children" (p. 208). According to Stanley, "the mothers' stories indicated that teachers and school administrators often disregarded this type of information, thus impeding their advocacy efforts" (p. 208).

MacLeod et al. (2017) noted that alternative explanations to the notion of a parent as 'outsider' include that "school staff and families do not always share the same goals and perspectives about disability and education" (pp. 382-383 citing Engel 1993; and Valle & Aponte 2002). Furthermore, MacLeod et al. stated that "teacher interaction with families of children with disabilities often uses a paradigm that reflects the dominant narratives of disability as deficit" (MacLeod et al., 2017, p. 383, citing P. M. Ferguson & Ferguson, 2006; and Zeitlin & Curcic, 2014). MacLeod et al., in discussing the work of Valle and Aponte, also noted that the professional, authoritative discourses of school professionals dominate and devalue parents and their discourse.

In their qualitative, phenomenological investigation regarding the parental voice within the special education process, MacLeod et al. (2017) explored efforts of parents to collaborate within the special education process framework so that they could garner support for their children with disabilities in general education settings. In their research, parents shared many concerns about collaborating with team members as well as described positive collaborative experience; parents, for example, discussed "persistent fears and anxieties due to lack of communication, trust, and negative perceptions of disability" (p. 381). Parents also shared "that positive collaborative experiences were more likely to occur when educators treated parents like partners, focused on the child's

strengths, explained ideas and policies clearly, and were flexible and willing to learn and try new things" (MacLeod et al., 2017, p. 381). The findings from MacLeod et al. supported research from Ferri and Conner (2005), P. M. Ferguson and Ferguson (2006), Bacon and Causton-Theoharis (2013), and Zeitlin and Curcic (2014) that "school professionals often reflect a dominant deficit view of disability" (MacLeod et al., 2017, pp. 395-396). Their research further supported the Hodge and Runswick-Cole (2008), Sauer and Kasa (2012), and Bacon and Causton-Theoharis (2013) by advocating a shift from a deficit-based view of a child with disabilities to an attribute perspective to achieve family-school collaboration and support the voice and viewpoint of parents. And last, MacLeod et al. reported that their findings support the work of Dabkowski (2004), Ferri and Connor (2005), and Sleeter (1995) that argued for a new way of communicating with parents during special education process meetings. These researchers sought to privilege the participation of parents during the special education process and minimize the medical, jargon-laden discourse of the dominant voices from professionals and educators, voices that focus on disability as a deficit. Hess, Molina, and Kozleski (2006) stated that if "we only give voice to the idea of empowerment without taking action, we are not truly providing families with opportunities to become equal partners in decision making for their children" (p. 156).

Chapter Summary

In this chapter, I introduced a theory of impact known as Critical Disability

Theory and discussed literature that surrounds it. Within that discussion, I presented

Foucault's theory of Power. I also considered four models of disability and how discourse, and specifically, CDA has been lacking as a frame when studying the notion of disability from any of the available models. I then turned the reader's attention to literature covering parent perceptions and the special education process. Within my literature review, I discussed one review of the literature that involved parent perception research concerning the special education process. This article captured all but one investigation before 2007. I also discussed parent-perception literature that examined parent perceptions concerning the special education process via surveys, via children experiencing transition, via children's experiences with inclusion, via children who are culturally and linguistically diverse, via the geographic location of the child, and via the child's category of disability or ability. Categories of disability and ability available for review concerning parent perceptions included investigations on children with Autism, children with behavioral disorders, children who are gifted and talented, children with intellectual disability, and children with multiple disabilities. Within this parentperception literature, researchers noted that parents discussed differentials in power between themselves and the team, school or district. Researchers also presented a parental need to advocate for their children with disabilities continually. Last, researchers reported compromised dignity (being devalued) for parents and children with disability, instances of inequity, and a lack of voice or say in the decision-making process.

CHAPTER III

METHODOLOGY

Overview

In this chapter, I present this investigation's research design, my role as researcher, the research context, methods of data collections and procedures, data analysis, and limitations regarding the methodology of this investigation. I discuss each of these areas in turn.

Revisiting the Study Summary

This qualitative investigation is a grounded exploratory, multiple case study design utilizing methodology and tools of critical ethnography such as CDA of perceptions held by parents whose children with disabilities are currently experiencing or who have experienced the special education process. To understand the dynamics of such meetings, one must critically examine specific instances of parental perceptions surrounding the discourses that occur during the formalized special education process; these discourses can serve to privilege, empower, disempower, alienate and marginalize, or unite and value. In this investigation, I utilize a multiple case design, a survey, openended-semistructured interviews and member checking to provide trustworthiness, authenticity, and credibility. I address hegemonic discourses that function to disempower parents and their children with disabilities as well as discourses that serve to unite and value parents and their children. I utilize grounded theory as a standpoint for data analysis. My primary, short-term goal of this project is to empower parents of children

with disabilities and provide them with a platform for voice. My secondary, long-term goal has four parts. First, I plan to inform at least one administrator and school staff so that they understand how discourses function to privilege, empower, disempower, marginalize, unite, or value others. At the least, I aim to make them self-aware of these issues when interacting with parents of children with disabilities. Secondly, I will provide training on this topic at the district-level training as well as state and national conferences. Third, I plan to develop a rubric and matrix that teachers and administrators can use during special education process interactions with parents to track and chart discourse instance types during IEP meetings. Last, I seek to develop statewide implementation of training for elimination or reduction of discourse types and actions that serve to privilege school staff and marginalize, disempower, and alienate parents and their children with disabilities by extension during the special education process.

Description of Research Setting and Social Context

I recruited most of the research participants—that is two-thirds of the participants (n = 10)—from a state within the southwestern U.S. I recruited the remaining participants—on third (n = 5) from a state within the intermountain region of the U.S. Within the Southwestern area, there is a metropolitan city with an urban core and numerous suburban pockets. There are stark, notable differences in economic situations. There are also large bilingual populations which predominantly include Hispanic individuals and Native Americans. Poverty is considered high. Crime, homelessness, drugs, gangs, poverty, a stagnant economy, illegal immigration, and a high rate of

unemployment are all significant issues within this region. On the other hand, within the intermountain region state, participants were recruited from three rural areas and a suburban region of a large city. Most of the population in this region are monolingual and White. Crime, homelessness, and use of drugs are below the national average, while poverty is slightly above the national average. The economy in this region, however, is healthy and unemployment is low.

Within the southwestern location, recruitment began in a suburban school district where I had received cooperation. This district, however, has fewer Hispanic and Native American individuals than the large neighboring metropolitan district; incomes and educational levels are also generally higher than the neighboring metropolitan district. Recruitment began in this suburban location as the metropolitan district denied cooperation; that is, I could not utilize district resources to recruit participants (parents of children with disabilities). Despite this cooperation denial, six of the fifteen participants, recruited via the snowball technique, reside within the boundaries of the metropolitan city school district.

Type of Study

This qualitative investigation is a grounded exploratory, multiple case study design utilizing methodology and tools of critical ethnography such as CDA of perceptions held by parents whose children with disabilities are currently experiencing or who have experienced the special education process. To understand the dynamics of such meetings, one must critically examine specific instances of parental perceptions surrounding the discourses that occur during the formalized special education process;

these discourses can serve to privilege, empower, disempower, alienate and marginalize, or unite and value. I utilized a multiple case design, a survey, open-ended-semistructured interviews, and member checking to provide trustworthiness, authenticity, and credibility. I examined hegemonic discourses that function to disempower parents and their children with disabilities as well as discourses that serve to unite and value parents and their children. I utilized grounded theory as a standpoint for data analysis.

Sampling Strategies

Below I discuss the sampling strategies I employ in this research project. I discuss ethnography, critical ethnography, and the process of multiple case-study design.

Ethnography and critical ethnography. In addition to utilizing grounded theory as my theoretical standpoint, I utilize methodology consistent with ethnography, specifically critical ethnography. In this investigation, "ethnography is both a process and a product" (Tedlock, 2000, p. 455). These two ideas are not exclusive but entwined. The participation of the participant, which allows them to voice their perceptions regarding special education processes, and the product, their voice. As a critical ethnographer, I study "social issues of power, empowerment, inequality, inequity, dominance, repression, hegemony, and victimization" (Creswell, 2012, p. 467). Importantly, as a critical ethnographer, I position myself in the text, being reflexive, self-aware of my role, and disclose biases and values (Creswell, 2012). While this is a non-neutral position, it allows me to advocate, as necessary, for the emancipation of marginalized parents and their children with disabilities within the current special education system. Also, importantly, in critical ethnography, "the data collection is less focused on time in the field or on the

extent of data and more on the active collaboration between the research and the participants during the study" (Creswell, 2012, p. 478). Moreover, because critical ethnography may help bring change that affects the lives of participants, "the participants need to be involved in learning about themselves and steps [that] need to be taken to improve their equity, to provide empowerment, or to lessen their oppression" (Creswell, 2012, p. 478). The interview questions encouraged reflection on their attitudes, feelings, and beliefs as well as what they know and understand about the special education process; the questions also explored reflexively attitudes, feelings, and beliefs as well as what participants didn't know and didn't understand about the special education process. As part of that reflexive process, I engaged in advocacy and education to reduce issues of marginalization or disempowerment. This engaged positionality aligns with the social justice component of CDT; it is a method for providing dignity to parents and their children with disabilities (Mažeikienė & Ruškė, 2011).

Multiple case study design. A second methodology that I utilize in this investigation is the use of multiple or repeated case study design. This methodology is consistent with and an appropriate tool for the grounded theory lens. Through this methodology, I focus on "developing an in-depth understanding" (Creswell, 2012) of the special education process via the perspective of fifteen parents of children with disabilities who are currently engaged in or who have gone through the special education process. About multiple case design, Yin (2003) wrote:

Each individual case study consists of a "whole" study, in which convergent evidence is sought regarding the facts and conclusions for the case; each case's conclusions are then considered to be the information needing replication by other individual cases. Both the individual cases and the multiple-case results can and

should be the focus of a summary report. For each individual case, the report should indicate how and why a particular proposition was demonstrated (or not demonstrated). Across cases, the report should indicate the extent of the replication logic and why certain cases were predicated to have certain results, whereas other cases, if any, were predicated to have contrasting results. (p. 59)

I utilized this multiple case design logic and methodology during this investigation within and across cases when engaged with participants and during critical discourse analysis and throughout the development of codes, themes, and relationships that arose from the participant's discourse.

As this dissertation presents perceptions of parents surrounding the special education process, I recognize the need to respond to issues of leadership, dignity, power, equity, and previous parent perception research specific to specialized instruction (special education) to name a few. With these ideas in mind, I intended to emphasize the relevance and value that parents provide when discussing educational concerns surrounding their children with disabilities. Thus, the next chapter will provide a review of the literature that yielded the theoretical conceptions behind my research. I will follow this with a description of the methodology, the findings (presented in two separate chapters), the discussion, the conclusion, and the implications of this study.

Participants

In determining sample size, I considered guidelines and research on saturation analysis from leading qualitative researchers. I also considered my available time frame for data collection, analysis, write up and defense. Moreover, I considered my expertise in specialized instruction (special education), the research investigation, and my budget for transcription services and small gifts given in gratitude for the participant's

participation. I discuss each of these areas below:

Research guidelines for participants in qualitative research. In considering the number of participants for this research study, I accessed the literature to provide a guidepost for my decision. Morse (1994, p. 225) and Bernard (2000, p. 178) recommended between 30 to 50 interviews and 30 to 60 interviews, respectively for ethnography and ethnoscience. For grounded theory methodology, Creswell (1998, p. 64) recommended 20 to 30 participants while Morse (p. 225) stated 30 to 50 participants. For phenomenology, Creswell (1998, p. 64) recommended 5 to 25 and Morse (p. 225) recommended at least 6. Bertaux (1981, p. 35) indicated that fifteen is the smallest acceptable sample for all qualitative research while Charmaz (2006, p. 114) suggest that "25 [participants are] adequate for smaller projects." Importantly, Green and Thorgood (2009/2004, p. 120) stated that "the experience of most qualitative researchers is that in interview studies little that is 'new' comes out of transcripts after you have interviewed 20 or so people." In a thorough review of the literature, Mason (2010), examined 2,533 qualitative investigations (560 of which fit the investigative criterion). Of those 560 qualitative studies, the number of study participants ranged from 95 to one, with measures of central dispersion equaling 31 (mean), 28 (median), 30 (mode), and a standard deviation of 18.7 (Mason, 2010). In Table 7, I provide a partial list of Mason's results concerning case study research, critical emancipatory research, discourse analysis, and ethnography of communication:

Timeline. After reviewing this literature, and considering my timeline for completion, I chose to end participant recruitment at saturation or up to 20 participants

Table 7

A Partial List of Mason's (2010) Literature Review Summary of Participant Numbers in Oualitative Studies

	No. of	No. of studies after	Ra	nge	Meası	ires of c	entral disp	ersion
Qualitative research type	studies found	inclusion criteria applied	High	Low	Mode	Mean	Median	SD
Case Study	1,401	179	95	1	40	36	33	21.1
Critical/emancipatory research	6	3	42	21		35	41	11.8
Discourse analysis	157	44	65	5	20	25	22	15.3
Ethnography of communication	1	1	34	34		34	34	

(parents of children with disabilities who are in the process of who have gone through the special education process), whichever came first, due to the limitation of time. This dissertation project was due by the middle of August 2017. As such, I had nine months to receive approval, gain access, conduct parent interviews and collect data from other sources, transcribe, code, analyze data, write the analysis, and defend the project.

Experience. As noted in my positionality statement, I have been a speech-language pathologist for 27 years (17 years in the school system) and have previously held special-education administrative duties; in other words, I have encountered thousands of children with disabilities and their parents and am familiar with their stories and experiences. This experience and familiarity with discourse analysis provided me with the skills, understanding, knowledge, and management necessary to see this project through. As such, I relied on the minimum numbers offered by Bertaux (1981) and Creswell (1994) as well as saturation analysis by Green and Thorgood (2009) to support my sample size election. I believed that saturation would occur at or before twenty

participants were interviewed.

Budget. For budget, I chose saturation, or up to 20 participants, whichever comes first, also due to the time commitment required to transcribe interviews. I alleviated this time commitment by utilizing *Same Day Transcriptions*, a CITI certified company that provided fast turnaround for transcriptions. However, at \$2.25 a minute, budget constraints had to be considered. To date, transcription cost has totaled \$1,400.

Access. For this study, I received full approval from Utah State University's Institutional Review Board (IRB) to proceed after submitting numerous documents. These included a *Letter of Exemption* (Appendix 2), a *Letter of Cooperation* (Appendix 3), a *Recruitment Flyer* in English (Appendix 4) and Spanish (Appendix 5), a *Letter of Informed Consent* in English (Appendix 6) and Spanish (Appendix 7). The *Letter of Cooperation* came from a research site (a small, suburban school district) in the Southwestern U.S. The gatekeeper was a special-education district representative. Initial introduction was through an email describing the study and participation request. After submitting documentation to the district, I received approval within five days from the district's research review board. Following approval, I coordinated with the gatekeeper to provide access to participants and to whom I guaranteed provisions for respecting the site and participants. At the same time, I also attempted to gain access to a large metropolitan school district in the Southwestern U.S. However, following application, and six weeks of waiting, the school district rejected the request for cooperation.

From this small suburban school district—the initial recruitment effort, a single notice in an electronic parent letter—netted eight potential participants who made contact

and indicated interest. From that initial eight, however, only three followed through with participation by signing the required Internal Review Board Letter of Cooperation.

I revised USU's IRB application three times. First, I included Snowball Recruitment (Merriam & Tisdell, 2015) via the recruited participants. The second revision concerned the addition of parent advocacy groups that were specific to my state of residence. Last, I submitted an IRB revision because of a necessary move (change in location). This last IRB revision included the request to recruit parents via known contacts from a rural county in an intermountain state as well as the Snowball Method should any participants come forward.

Through the Snowball method, I recruited ten of fifteen participants, although I found this alternative process to be time-consuming. In the Southwestern State, neither advocacy group (second IRB modification) returned emails or phone calls regarding cooperation requests.

Participant Demographics: Aggregated Data

I gathered participant demographic information during the Qualtrics on-line Survey. Participants responded to questions about location, household number, number of children with a disability, number of children on an IEP or IFSP, disability categories, level of education, employment status, occupation, family income, age, gender, ethnicity, and school type. I present this data below.

I collected data on the participants' place of residence. Within this study, three participants (20%) lived in a large city or urban area. Six participants (40%) resided in a suburban area. Another five participants (33%) were in a small city or town. I had one

participant (7%) from a rural area but not on a farm or ranch. This range of habitats indicates that within this 15-participant sample, there is diversity in living situations. These differences may also show a wide variety of possible special education process experiences (see Table 8).

Family Demographics

In the demographic questions 35 through 39, I asked participants about their household. I wanted to understand the family unit that pertains to each case. I collected data on how many family members there are, how many children are younger than 17, how many children younger than 21 have a disability, how many children younger than 21 are on an IEP, and how many children younger than 3 are on an IFSP. These data provide insight into participant responses within the survey and during the interview. To summarize the information, I present the minimum value for each question, the maximum value, the mean, and the variance.

Number in household. I asked participants about the family unit residing in their home. Within this study, there is a minimum of three occupants and a maximum of six. The mean number of occupants is 4.27 (0.68 *SD*; see Table 9).

Table 8

Q34. General Residence Location

#	Answer	%	Count
1	Large city or urban area	20.00	3
2	Suburban area	40.00	6
3	Small city or town	33.33	5
5	Rural area NOT on a farm or ranch	6.67	1
	Total	100.00	15

Table 9

Q35. Including Yourself, How Many People Do You Have Living in Your Household?

Field	Minimum	Maximum	Mean	SD	Variance	Count
Including yourself, how many people do you have living in your household?	3.00	6.00	4.27	0.68	0.46	15

Children, age 17 or younger. As a refinement question, I asked participants about the number of children in the household, 17 or younger. Within the study, there is a minimum of one child in the household to a maximum of four. The mean number of children is 2.33 (0.62 *SD*, see Table 10).

Children, ages 21 or younger with a disability. Regarding the children in the household, my interest is how many have a diagnosed disability. Children can have a disability, but not be on an IEP and adult children with a disability can remain on an IEP until age 22 if they present the need before they age out of the special education program. As such, I asked participants about the number of children in the household, 21 or younger who had a diagnosed disability. Within this study, there is a minimum of one child to a maximum of four who are 21 or younger and have a disability. The mean for this group of children is 1.53 (0.81 *SD*; see Table 11).

Children, ages 21 or younger on an IEP. As mentioned in the previous section, there can be a difference between the number of children with a disability and the number of children receiving specialized instruction; that is, on an IEP. As such, I asked participants about the number of children, 21 or younger, who are currently on an IEP. Within this study, there is a minimum of 0 children to a maximum of three who were 21 or younger and on IEP. The mean number of children is 1.40 (0.71 SD; see Table 12).

Table 10

Q36. How Many Children, Age 17 or Younger, Do You Have Living in Your Household?

Field	Minimum	Maximum	Mean	SD	Variance	Count
How many children, age 17 or younger, do you have living in your household?	1.00	4.00	2.33	0.79	0.62	15

Q37. How Many Children, Ages 21 or Younger, Do You Have That Have a Diagnosed Disability?

Field	Minimum	Maximum	Mean	SD	Variance	Count
How many children, ages 21 or younger, do you have that have a diagnosed disability?	1.00	4.00	1.53	0.81	0.65	15

Table 12

Q38. How Many Children, Ages 21 or Younger, Are Currently on an Individual Education Plan?

Field	Minimum	Maximum	Mean	SD	Variance	Count
How many children, ages 21 or younger, are currently on an IEP?	0.00	3.00	1.40	0.71	0.51	15

Children age 0 to 3 on an IFSP. As a final question about specialized instruction, I asked participants about the number of children in the household, birth to three, who are on an Individual Family Service Plan (IFSP). In this study, there are no children in this age range identified as being on an IFSP.

Demographics—Disability and Other

Table 11

Survey questions 40 through 44 concerned the participants' child or children with a disability(ies). I asked participants how the school system had classified their child or

children. Participants identified a minimum of one child with a disability and a maximum of four in their family units. This information was valuable because the category(ies) are informative. They help me understand potential issues that family units may encounter within the home and school system. It informs both the survey and interview responses as children with different disability types typically have different needs. In Table 13, I summarize those results based on participant responses.

My participants identified a total of eighteen children with a disability (Table 13).

Table 13

Q40-44. What are the Classifications of Disability or Exceptionality for Your Child or Children?

	Children	Children		Disability cate	egory(ies)		Children
Participant	with a disability	identified exceptionality	Child A	Child B	Child C	Child D	with an exceptionality
Evelyn	1	1	SLI				G (Child A, TE)
Sandy	1		MD				
Robert & Angie	2		A, OHI, BD	SLD, OHI			
Carrie	1		SLD, SLI				
Dave & Meagan	2	2	SLI	SLI			G (Child A, TE) G (Child B, TE)
Janet	2		SLD	A			
Danielle	1	2			OHI		G (Child A & Ba
Rebecca	1		SLD				
Joy & Rex	1		SLI (MERLD)				
Diane	4		A	MD, OHI, SLD, SLI	HI	A	
Jennifer	1		SLI (MERLD)				
Robin	1		ID				
Total	18	5					

Note. SLI = speech-language impaired; MD = multiple disabilities; A = autism; OHI = other-health impaired; BD = Behavior Disorder; SLD = specific-learning disability; MERLD = mixed expressive-receptive language disorder; ID = intellectual disability; G = gifted, TE = Twice Exceptional.

^a Child A & B, excluded as only Gifted Classification.

In this table, I also show that five children are considered exceptional (gifted). Of those five children, three also have a disability (speech-language impaired in each case); as such, these three children are considered 'twice exceptional.' The other two children (children of *Danielle*) are identified here in Table 13 but are not part of the results of this investigation. *Danielle* only discussed them tangentially. The focus of her case is on her third child, Peter.

In Table 13, I also show that some children have multiple classifications of disability. Six of the 18 children are reportedly speech-language impaired. Two of the 18 children have multiple disabilities. Four of the 18 children in this sample have the classification autism, and four have the classification other health impaired. Three of the 18 children are reported to have a specific learning disability. Last, of the 18 children, 1 has a behavior disorder, 1 is hearing impaired, and 1 has an intellectual disability.

Education. An important question in this research survey is the participants' level of education (Figure 4). In my view, it informs the types of responses obtained during the survey and to interview questions; likewise, it informs actions taken, perceptions held, and belief systems. Within this study, all participants report education that extend beyond high school. One participant (7%) has some college experience, two (13%) indicate they hold a 2-year degree, six (40%) stated they have a 4-year degree, and the remaining six (40%) indicate they have an education that extends to a professional degree.

Employment status. Within this study, nine participants (60%) are employed full time, four (27%) are unemployed and not looking for work, one (7%) is a student, and one (7%) reports being disabled (Figure 5).

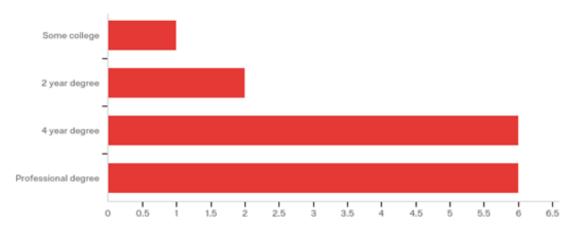


Figure 4. Education level.

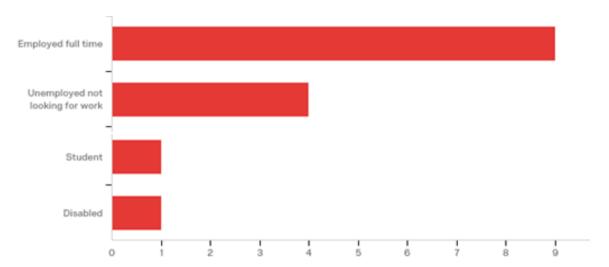


Figure 5. Employment status.

Occupation. Eleven of 15 participants report an occupation (Table 14). In this investigation, participants identified the following occupation fields: construction (1, 9%), education (3, 27%), computer/technical (1, 9%), tourism (1, 9%), finance (1, 9%), medical (2, 18%), and other (2, 18%).

Household income. To understand my participants' socioeconomic statuses, I asked participants about their family, household income (Figure 6). The selection of

Table 14

Q47. What Is Your Current Occupation?

#	Answer	%	Count
2	Construction / carpentry / plumbing / electrical / craftsman	9.09	1
5	Education	27.27	3
8	Computer / technical / electronics	9.09	1
9	Restaurant / hotel / tourism / entertainment	9.09	1
12	Finance / insurance / real estate	9.09	1
14	Medical / wellness	18.18	2
16	Other	18.18	2
	Total	100.00	11

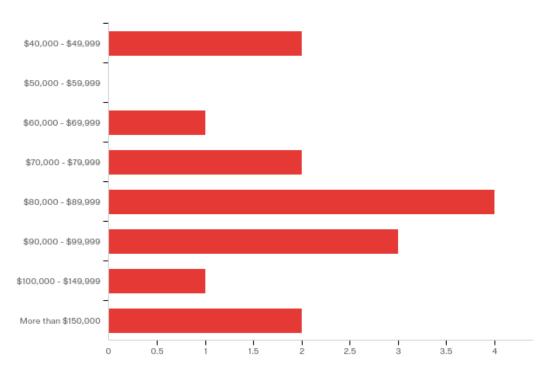


Figure 6. Income before taxes last year.

household income was purposeful. I wanted to capture the full household income as it adds to the overall picture of SES. Two participants (13%) report the range of \$40,000 to \$49,000 for household income, another participant (7%) reports the range of \$60,000 to \$69,000 for household income. Two participants (13%) state family household income to be in the range of \$70,000 to \$79,000 and four list \$80,000 to \$89,000 as their family income. Three participants (20%) report the range of \$90,000 to \$99,000, one states the range \$100,000 to \$149,999, while two (13%) indicate they are within the top category, 'more than \$150,000.' As such, household income for this dissertation study is relatively high. Most participants in this study appear to have resources that families considered lower SES would not have.

Age. I also asked participants their age (Figure 7). Within these research project, three participants (20%) identify themselves as 25-34 years of age, six (40%) indicate the age range of 35-44, four (27%) list their age range as 45-54, and two (13%) state their age range as 55-64.

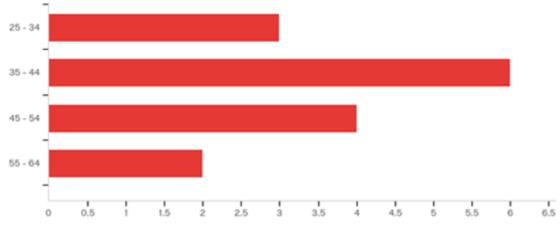


Figure 7. Age.

Gender. Participants responded to the question, "What is your gender?" Within this study, 12 participants (80%) are female, and 3 (20%) are male.

Race or ethnicity. Participants responded to the question, "What races or ethnic background do you consider yourself?" Within this dissertation project, 13 participants (87%) identify themselves as White or Caucasian, 1 participant (7%) states other, and 1 participant (7%) reports, don't know.

School type. Participants responded to the question, "What type of school does your child attend?" Within this question, 14 participants (93%) indicate their child attends a public school, while one participant (7%) states a charter school.

Participant Descriptions: Disaggregated

The number of participants for this investigation was in its inception to end at saturation or up to twenty participating parents who have or have had children with disabilities go through the special education, whichever came first. Participant recruitment ended at fifteen participants. However, only 14 participants completed the interview portion of this investigation; that is, one participant (Robin) moved during data collection I could not reach her despite repeated attempts to make contact. Fortunately, saturation of codes and themes had already begun during coding of participants eleven (Joy) and twelve (Rex). No new codes or themes emerged during coding for participant thirteen (Diane) or participant 14 (Jennifer). These participants, however, helped solidify theme relationships. In the following section, I explain the methodology I used to create the participant portraits.

Participant portraits. To create portraits, I used the following minor themes:

demographics, participant concerns, concerns action, participant/child/family introductions. The data for these themes came from two data sources. The first source was the survey. I utilized their disaggregated responses to demographic questions to help describe and frame categorically who these individuals are. Additionally, I also used their responses to two content survey questions, specifically current concerns and what they might choose to do about those concerns (concerns action). To add richness and depth to those participant profiles, I utilized the text from interview data coded as participant introductions, child introductions, or family introductions. Also, to support child descriptions in the participant portraits, I used their discussions regarding the initial identification of their child or children with disabilities. Last, I also included current concerns text expressed during the interview.

As an introduction, the participants for this investigation reside in either a Southwestern state (n = 10) or within one of two states in the Intermountain region of the U.S. (n = 5). Five participants were in a suburban school district, five resided in a large metropolitan city and district, and five lived in small rural cities/towns and school districts.

Evelyn. Evelyn is a White, married woman who is 25 to 34 years of age. She lives in a small suburban city in a state located in the Southwestern U.S. With a professional degree, she is employed full time in a finance/ real-estate/insurance trade. She reports that gross family income is \$40,000 to \$49,000 a year. Evelyn has a son, Sam, who, at time of data collection, was in the eighth grade. He attends a public school. For a time, when Sam was younger, he was in Special Education services in an Eastern

Time zone state. *Sam* first had speech services, and then they enrolled him into a Gifted program; as such, he was 'duel enrolled' 'or 'twice-exceptional;' that is, he had an IEP for both specialized and gifted instruction, a combined IEP. When Evelyn and family moved to the Southwestern State where data collection took place, Sam was released from speech services and was just receiving Gifted-only IEP services. When asked to introduce herself and her child, Evelyn was matter-of-fact. She initially provided few details:

Okay. My name's Evelyn. My son's name is Sam, and he's in eighth grade now. He was originally enrolled in State A with Speech and then into the Gifted program, so we had an IEP for both--a combined IEP. And then when we moved here, he got off Speech and just went into the Gifted only. (Evelyn, personal communication, April 7, 2017)

Early in the interview, when she was discussing his IEP classifications, Evelyn opened a little more about Sam's unaddressed background.

He has kind of—he is on the autism spectrum because we haven't had him fully diagnosed. My father-in-law is a child psychologist who diagnoses autism in children and so when we moved here, and he had more interaction with Sam, it was, "Yeah, he's on the autistic spectrum. If you want to get him in, I can tell you the right things to do." (Evelyn, personal communication, April 7, 2017)

After hearing this, Evelyn's survey responses regarding current concerns about her son, *Sam* made more sense. In her survey, Evelyn reported being concerned about the following issues regarding Sam: adequate socialization, having friends, being labeled and teased, learning to communicate with adults, and being understood. These are typical concerns for a parent who has a child on the autism spectrum, diagnosed or not.

As we talked, and Evelyn appeared to relax and feel more comfortable with the interview, she expressed her current concerns more deeply. She is specifically worried

about the upcoming school year for her son, Sam.

My biggest concern right now with him is being that he's transferring into—he's going into high school—is what kind of things are in high school that, you know, right now, that as a parent in middle school, he has a full class. In high school, there's nothing. School A has absolutely nothing, and that's where we're zoned. So, Teacher A, you know, explained to me that there is kind of a transition type class at School B. Maybe it's not going to be there next year or maybe it is.

Sandy. Sandy is a white, married woman who is 35 to 44 years of age. She lives in a small suburban city in a state within the Southwestern U.S. Sandy has a 4-year degree, but is unemployed and not looking for work. Her husband, Jim, is a pharmacist and as a family, they make \$60,000 to \$69,000 a year. Sandy is a mom to three children. Two of the children are 12 and are twin boys. Sandy describes the boys as being "pretty normal" (Sandy, personal communication, April 6, 2017). Here's Sandy in her own words.

Okay. I am Sandy, and I am a mom of three kids. Two of them are 12, and they are twins, and they are boys, and they are pretty normal boys. And then I have a daughter that's 9, and she is the special-ed student. I have a husband. He is a pharmacist. We are married, and we all live together at home. (Sandy, personal communication, April 6, 2017)

Sandy 's daughter, Chelsea, now 9, receives special education services. She is a child with multiple disabilities in the public-school setting. Sandy is worried about Chelsea's adequate academic yearly growth, adequate socialization, her being labeled or teased, being bullied, her ability to learn to read, learning skills necessary to get a job, learning to communicate with peers, and being meaningfully employed. Sandy reports noticing problems with Chelsea at around age 3.

All her milestones were normal. She talked, she was—she seemed normal. And then right around three was where she wasn't following along with the songs that we would sing. She wasn't following along with books that we would read.

Colors weren't coming to her or like she just wasn't catching on to the regular way the other two did. (Sandy, personal communication, April 6, 2017)

Angie. Angie, a white female, is 45-54 years of age. She lives with her husband and two adopted children who both have with disabilities. They live in a large, metropolitan city in the southwest U.S. and earn \$70,000 to \$79,000 a year. Angie has a 4-year degree and is employed full-time in the field of education. She works in the public schools and has done so for the past twenty years. Her children attend public school. Thomas, her oldest son, is in ninth grade. He has autism, mental health issues, and behavioral needs. Angie's youngest son, Timothy is in seventh grade. His needs are different from his brother: he has academic learning challenges as well as Attention Deficit Hyperactivity Disorder (ADHD). His classification is a specific learning disability. Timothy has been on an IEP since third grade while Thomas began an IEP in fourth grade. Angie concerns surrounding her boys are issues of adequate socialization, having friends, learning writing skills, and learning to communicate with peers and adults. Here is Angie in her voice:

Okay. My name is Angie. I am an occupational therapist. I work in the schools. I have done so for about 20 years. I am very familiar with the IEP and special education process. I also have two kids that are on IEPs. One has more behavioral needs. The other has more academic needs. Let me see. The younger one has been on an IEP since third grade, and he is now in seventh grade. The other one I think was fourth grade and he is now in ninth grade.

I asked for clarification, about who was who. Angie replied, "the older son—the ninth-grader has autism as well as some other mental health issues. The seventh grader has the learning disability. He also has ADHD" (Angie, personal communication, May 8, 2017). I then asked Angie to expand even more. To give me some insight into who they

were as children. Angie responded:

My son—his name is Thomas. He is the one with autism who is in ninth grade right now. I had to kind of fight to get him an IEP. I guess I should say I started with speech and language concerns. They were language concerns, not speech concerns. Having a conversation with him was difficult. He would say just really off the wall things. I asked the school to do a language screening, and of course, he passed it because a language screening is pretty basic and simple. He can interact on a basic and simple level. That was in first grade. I got the story about how he is getting good grades, so it is not impacting him educationally. I am like I get that. I work with kids in special ed. I understand that. However, he cannot carry on a conversation. Maybe if he had been older, I could have made that argument a little better. Probably a lot of first graders cannot carry on a conversation, but my son's [issues] went a little deeper than that. It took another couple of years.

It was not until third grade, which is typically in my understanding the year that kind of when things get real. That is when a lot of kids get referred for special-ed because third grade is kind of tough. That is when the academics kick in I think. I think teachers to that point are like they will catch up. He did not. Finally, his third-grade teacher agreed with me that there were some pretty significant concerns with his language and written expression.

He was initially on an IEP under OHI because of his other diagnoses. He has reactive attachment and some other kind of ADHD type behaviors. They just put him on an IEP under OHI. Then he got an outside diagnosis of autism spectrum disorder, so then the school did their own. He was up for a re-eval and did an autism eval. Then he was exceptionally changed to autism. The whole process was I felt like if I had not had my own experience working with special ed, I never would have known to kind of push and sort of force the issue in a very polite way.

My other son, [Timothy], I think was a little more typical kind of process. He was having trouble in school. Again, I spearheaded it and brought it up. I was the one who was like he is really struggling. You do not understand how much he struggles to try to get his work done and how stressed he is about school. I feel like I might have pushed it a little. His teacher at the time, it was kind of towards the end of the school year. I think she was just going to put it off until the following school year. I was like no. You are going to put the paperwork through now. He got tested over the summer. I feel like because of my experience working in special ed; I was able to sort of be a little bit more proactive than maybe a typical parent. (Angie, personal communication, May 8, 2017)

Robert. Robert is the spouse of Angie (described above). Robert lives with Angie

in a large metropolitan city in a Southwestern state. He is 55 to 64, has a professional degree in education, and reports their combined income is \$80,000 to \$89,000 a year as a family. He identifies himself as "other" concerning race/ethnicity. Robert has two older children and two younger children that his wife adopted just before they met. Thomas, the oldest, just turned 15 and he has multiple diagnoses, primarily Asperger/Autism Spectrum Disorder. Thomas also has Reactive Attachment Disorder and a host of other behavioral issues resulting from trauma in his birth home. The younger son, Timothy, age 13, has an ADHD diagnosis and is treated with medication. Robert, however, does not believe that the medication works all that well, stating that he's not hyperactive, but has some serious attention issues where he'll forget something immediately upon you telling him. Robert's most significant concerns now for his two boys are slightly different from his Angie's, his spouse. His concerns include: adequate socialization, having friends, learning to decode text in written language, learning skills necessary to get a job, learning to communicate with peers and adults, being understood, and being meaningfully employed.

During the interview, I ask Robert if the two boys had special education services before the actual, final adoption which was in August of 2007. He replies:

...we didn't think there were any problems at the time. I mean there was some behavior issues that Angie noticed especially with Thomas but for me coming from having raised two neurotypical kids. They um, uh, they seem to me just to be like normal little boys, you know. And, and a lot of, I think a lot of behavior, too, considering how they were when she first got them, they were just little hellions, I mean from what, what I heard from her. They just you know, ran wild, so um, nothing, nothing at first, no. (Robert, personal communication, May 8, 2017)

Carrie. Carrie is a white, divorced female who is 55 to 64 years of age. She has

three children. She lives in a small suburban city in a state within the Southwestern U.S. With a professional degree, she is employed full time in a medical/wellness profession. She brings in \$80,000 to \$89,000 a year. Her third child, Max, is in 11th grade and attends a public high school. His special education category is Other Health Impaired. Carrie is concerned about Max having adequate yearly academic growth. She is concerned about teasing, his ability to learn skills necessary to get a job, and with his ability to communicate with peers and adults.

Carrie introduces Max, his educational story, and trouble she encounters with a diagnostician for specialized instruction. Carrie states Max has had difficulty in school from day one:

He's the youngest of three, so I thought well, he'll catch up. No big deal. No worries. By fifth grade, his elementary school teachers were telling me no, no. This is more than just a little bit behind; he's not getting it. You need to have him tested. So, I knew he had issues with math because he couldn't memorize math facts. But I didn't think the issues were any greater than that. Well, when they tested him, they told me he had a specific learning disability in language processing, [with difficulties in] comprehension, reading, written expression, and oral expression.

And that surprised me because I didn't see that. But *Max* couldn't find answers to questions at the end of a chapter in the social studies book. He couldn't write papers to save his life. That kind of stuff. So, I'm like okay. So, in middle school, he started some services, SLP, and some special ed services to help him with all of that.

And it helped but he still struggled, and his grades varied from A's to F's, depending on the day and the topic and the class and the teacher and all of that. So, I spent a lot of time at home in the evenings basically tutoring him in math, tutoring him in social studies, tutoring him in whatever the topic was. Because he just didn't get it during the day.

So, everything took way longer than I thought it should. But that worked to keep Max kind of in the C range. So, no issues. Well, at the beginning of this year, he's in Eleventh grade now. So, at the beginning of this year, I asked the Diag.

[Diagnostician] to help me figure out exactly what the issue was because I'm worried about him. When he graduates from high school, then what? Because it's more than just language processing. There's something else going on. He just really has a hard time, and it affects all areas of his life. He played basketball. He ran track. He ran cross country, and he missed instruction there too. The coach would tell him we're taking the bus. Be here at six o'clock in the morning. And he didn't know if there was a bus, what time it was leaving. And we spent a lot of time chasing down information through his friends to make sure he didn't miss anything important.

So, I could tell that it's not just a school issue, it's a life issue. So, I wanted more help with that. So, the Diag. said sure. She could help try to figure that out. So, she tested him last fall and came back with an evaluation in January. Saying [that he] no longer qualifies for special education, that his IQ and his achievement level were equal and in the average range.

So, he didn't qualify anymore, and they were going to exit him from Special Ed. So, his IEP was scheduled for March, and they were going to just take him off the IEP. And he has his whole senior year ahead of him, and I was terrified. I thought what's going to happen if he doesn't have any special-ed support? He had 17 hours up to that point, 17 hours a week. (Carrie, personal communication, May 24, 2017)

Meagan. Meagan is a white female who resides in small, suburban city in the Southwestern U.S. She has a husband, Dave (described below), a computer specialist who works for the government, and two children, April and Heather, both of whom have Speech-Language Impairment. Meagan has a 4-year degree, but is currently unemployed and not looking for work. The family reports income of more than \$150,000 a year and her children attend public school. Meagan's primary concerns now are that her girls are understood and that they learn to communicate with peers and adults. In opening her conversation, Meagan talked about the effects of growing up in and around the military with her and her children:

So, I'm Meagan. My dad was from [Country A], so, I grew up hearing an accent all the time. I clue into things like that. I was in a gifted situation in my academic career, and I married a man who was also very, very bright. He was in the

military, so we traveled all over the place. We were in [State A], [Country B], [State B], [State C], [Capital A], [State D]. We waited 13 years to have our first daughter because we didn't want to have a child having to move. We thought that would be disruptive. My primary focus was getting my college degree finished. I started in [State A]. Ended up going to [Country B], and they closed the academic portion of the base because they were drawing down.

So, I was one semester from graduating with my bachelor's in psychology. And they closed the base. So, it was a great thing, because then we ended up just taking classes. I ended up taking some sociology classes for fun. I enjoyed them. So, we were stationed in [State B], and I was able to finish my bachelors of sociology with 300 elective credits. And graduated with a year to kind of play around in [State B]. And then, we moved to [State C]. My husband was picked up for officer training and, so we moved to [State C]. And I started a program at the University of [State C]. It was a dual degree program. I was the first candidate invited to the program.

I was a test case. And they wanted me to get my Ph.D. in sociology along with my Juris Doctorate. And I did the first year of the program. I did very, very well. But we decided it was time to have our first daughter because I was 32 and they talk about age and all of that. So, it was time. So that's all on hold right now, and my primary focus is my kids. We had April. I was 32, and then we had Heather when I was 36. And, um, both of the girls are incredibly bright and keep me very busy.

When she [April] was three, we were looking at—thinking about Kindergarten, because she was already reading, and writing, and doing math in her head. And we knew that school was going to be important for her. And we knew that she had a September birthday and, so we were trying to figure out would we hold her back the year, or would we go ahead and let her start. We were moving to [State D]. The age cutoff was September 13th. Her birthday's September 11th. It was so close that we weren't quite sure.

So, when she [Heather] was a baby, I knew something was wrong. You know how you just know with your kids. I know my kids. I spend a lot of time with them. I talk to them. I listen to them. She started speaking complete sentences when she was; I would say, 10-11 months. It was right in there. It was before she was one, I know it for sure, but I can't tell you if it—I know April started speaking at nine months. And I think Heather was, like, ten-ish. She said, 'Where did Grammy go?' Which is not what a ten-month-old usually says. And then she stopped talking. (Meagan, personal communication, May 22, 2017)

Dave. Dave is a white male who resides in small, suburban city in the

Southwestern U.S. He has a spouse, Meagan (described above) who has a four-year

degree but is unemployed by choice so that she can raise their two children, April and Heather, both of whom have Speech-Language Impairment. Dave has a professional degree, works full time, and earns more than \$150,000 as a computer specialist while working for a government agency. Dave had fewer concerns with his daughters than Meagan. His concerns are that they not be labeled, that they learn to communicate with adults, and that they are understood. He began his interview in this manner:

Okay. Well, mainly for me, it's because of the kiddos. While they both are gifted, they had issues to deal with. They seemed to go hand-in-hand. And I mainly got interested, got involved with it, because one, I'm interested in education. But a lot of times, it seems like—you know, [School A] is different. But I definitely noticed the other schools; they don't take Meagan seriously unless I'm sitting there. Which is insane, because as you've experienced, she's more than capable of articulating and defending the children. This may be a [State A]-ism, but unless the dads there, they don't seem to—it's just a whiny mom or something. (Dave, personal communication, May 22, 2017)

Janet. Janet is a divorced, white female with triplets. She resides in a suburban area of a large metropolitan city in the Southwestern U.S. Janet has a 4-year degree in the medical/wellness profession but is now disabled. She reports her income as \$40,000 to \$49,000. Her children attend public school, and two of her children have disabilities. When identifying her current concerns, she thought of her daughter Shawna who has a Specific Learning Disability. Janet is worried about Shawna's yearly academic growth, her learning to read, write, and develop math skills.

In describing Shawna, Janet says, "So, Shawna went from like, having recognizing [abilities] to not being able to recognize letters and certain things anymore.

And it was a very bizarre thing to me" (Janet, personal communication, May 22, 2017).

She continues:

[In Kindergarten], they're learning sight words and things like that. And she struggled. And now the child is really bright, but struggled with 'the' and 'to' and 'too,' and- All the basic- 'When,' 'what,' 'where's,' could not get these, no matter how many repetitions, she could not get these down. And the other two, well, she's a triplet. And the other two picked up on it fine. Now, I don't expect everybody like, I never expected them all to perform the same things at the same level, because they are three people, three totally individual children with individual strengths and weaknesses. But I had a benchmark. Like, I had, in my home benchmark. And what I was seeing with her, it wasn't even a progression; it was like a regression. (Janet, personal communication, May 22, 2017)

After speaking about Shawna, Janet turns her attention to Maci, a daughter with Autism (Pervasive Developmental Delay-Not Otherwise Specified) (PDD-NOS). Janet states that Maci used to be on an IEP that originated in a New England State, but is no longer receiving specialized instruction (on an IEP) due to her progress:

That's the autism. So, that was the, with Maci and her and her sisters all had speech therapy. They were 29 weeks, very premature. And then Maci was the one that had, was diagnosed with PDD-NOS. And [she] received probably 20 hours a week of in-home therapy. I mean, the speech pathologist said, I have never seen a child so far behind come so far ahead. (Janet, personal communication, May 22, 2017)

In describing what she saw early on with her daughter Maci, Janet says:

It was stuff like, I know this sounds weird, but I would make grilled cheese. It was a common food I would make them. And I had this triplet feeding table, the c-shaped table. And I would make grilled cheese, and I would rip off pieces. And it was suddenly ripping this; it would cause this child to just decompensate. Or she would sit in a corner, I mean, and it was clearly related to this action. There was something about what I did was very disturbing. And it would, and it was regular. These kinds of behaviors were regular enough that I'm going, that's not a normal response to that. And then like, she would play with blocks for an hour. She could focus and play with something for an hour. (Janet, personal communication, May 22, 2017)

Danielle. Danielle is a 35- to a 44-year-old white female who lives on a base in a large city in the Southwestern U.S. Danielle has a 2-year degree, but is not currently working; instead, while on the base, she helps other moms who are having difficulty or

need support. There are five in her family; she has a husband who is an officer in the military and Danielle reports that their income is from \$100,000 to \$149,000. They have three children. One child, Peter, is on an IEP and is classified as Other Health Impaired. For Peter, Danielle is worried about his yearly academic growth, his socialization skills, and his ability to adequately communicate with peers and adults. All her children attend public school. Danielle describes her background and family as follows:

Okay. I have my associate's, but I am on my way to my bachelor's. I started my college education in 2000, and I stopped in the fall of 2001 because my oldest child was due before finals. I was not willing to pay the money if I was not going to get the credit. I was away from the classroom for about 13 years. Went back when we were living in Germany, and our youngest child was in the local school, so after six months, he had German. He knew it. He thought he was German. He was 3 years old, so he was right at that age to learn. He stopped talking to us in English and started telling us, no in German. "Nein, Mama. Ich bin Deutsche. Sie müssen Deutsch sprechen." No, Mommy. I am German. You have to speak German.

His teachers at the preschool recommended that I take a German class. I had a friend who was signed up for one at one of the local universities that were servicing the military. She said to contact the class. They are about ready to cancel it if we do not have more students, anyway. You need to, so I started that.

My husband is a graduate of [University A] and has two master's degrees. Education has always been a priority for us. I did not know him as a youth, so I do not know how his education was for him. I do know that his mom tells stories that he had teachers that would complain, "Your son is sleeping in class." She goes, "What is his grade?" They go, "Like, a 99." She is like, "Fine. Leave him alone." Education came easily to him. I was a military kid when I was growing up. I thought the proper way to register for school was to be evaluated every single time. I thought you had to take a test to get into school because that is what my mom did. I was in the gifted programs in _____, ____, and _____. I was familiar that there were gifted programs, but each state is different. Up until graduating high school, I did not realize I was in them. I just thought they were part of our classes (Danielle, personal communication, May 25, 2017).

In describing her children's home environment, Danielle compared herself to other families in the area:

I do not think our family is that unique. I really do not. We are a bilingual family, sort of. My husband speaks Spanish fluently, Italian, French, Portuguese, not quite fluently, and I say his German is passable and he says it is okay. My German is enough to get me around. They have grown up in a house where they are just allowed to learn whatever they want to learn when they want to learn it (Danielle, personal communication, May 25, 2017).

During the interview, Danielle also describes the process for getting her two of her children, Elizabeth and Peter onto IEPs in their current district; Peter is currently undergoing evaluations for ADD/ADHD as well:

At registration for Elizabeth going to fifth grade and Peter going into second grade, I signed the little paper, and I said, "When can I have them tested?" I started asking on registration. I was told [by a large metropolitan districting in the Southwestern U.S. that they] did testing according to grade level at set times. Elizabeth received her testing first because fifth graders were first. Peter received his testing later. I can email you those exact dates if you need to for the first time that they were like, "Yes, we are going to think about testing Elizabeth, her IEP I think was in November, so it took it from August until November for her to get fully tested and in. By November—I think it was the 30th of November, so it was almost December.

Peter, his testing did not even happen until the second semester. It did not matter how many times I asked. "We do not do that testing now. He needs to wait for the second graders." He went and did the testing, and he got his IEP about a month ago, so it took them a full school year to do this. (Danielle, personal communication, May 25, 2017)

Rebecca Rebecca is a white 25-to 34-year-old married female with two children. Rebecca and her family live in a suburban area within a large metropolitan city in the Southwestern U.S. She has a professional degree and is employed full time in an "other" profession; family income is in the \$80,000 to \$89,000 range. Her oldest son, Garrett, is currently 11 years of age, in seventh grade, and in a gifted program; Garrett also has learning challenges. He demonstrates difficulty with executive functioning skills such as time management and organizing his thoughts; he also has occupational therapy. Rebecca reports that neither area of Garrett's needs is currently being addressed by the large metropolitan district in the Southwestern U.S. despite requests for support. Rebecca

worries about Garrett's yearly academic growth, his ability to move to the next grade, having friends, learning to decode text in written language, and learning to communicate with adults. Rebecca describes Garrett's early years and unaddressed learning challenges in the following manner:

Okay. He, well, he had seizures for the first four and a half years of his life. He had a severe reaction to immunizations. And it took many, many visits with a neurologist to determine what it was. And once we stopped the immunizations and put him on a different immunization schedule, a more specific one for him, the seizures stopped.

But he is not able to sorry. My mind won't think. He has trouble organizing thoughts. He had trouble organizing ideas. When he's retelling a story, his skills are behind by about six months. Or they were up until this year, until his sixthgrade year.

His vocalizations don't match with his writing. His handwriting is still very rudimentary. It's almost like a second-grade child is writing. (Rebecca, personal communication, June 7, 2017)

Joy. Joy is a white 35-to 44-year-old married female with two children. They live in a small town or city within the Intermountain region of the U.S. She has a 4-year degree and is employed full time in the Restaurant/ Hotel/ Tourism/ Entertainment industry as a director. Her husband, Rex (described below), works in construction; she reports family income to be is in the \$70,000 to \$79,000 range. Joy has many concerns regarding her daughter, Sierra, age 9. Her concerns include adequate yearly academic growth and socialization. Other concerns for her daughter include having friends, being labeled, teased, bullied, moving to the next grade, learning reading, math, and writing skills, learning to communicate with peers and adults, and being understood. In describing her children, Joy remarked:

We have two kids, Sierra and Jessica. Sierra is nine, well, she'll be ten tomorrow, and Jessica is six. Sierra has been on an IEP since preschool. Yeah, so Sierra has

been on an IEP since preschool, and we've had good years and bad years. I think I feel like we have a ... I mean she's going to be in fifth grade next year. (Joy, personal communication, June 24, 2017)

Rex. Rex is the spouse of Joy (described above). Rex is also white and 35-to 44-years of age. Rex and Joy have two children. They live in a small town or city within the Intermountain region of the U.S. He works in construction and owns his own business. His wife, Joy, works in the restaurant/hotel/tourism/entertainment industry as a director; he states that family income is in the \$90,000 to \$99,000 range. In describing pressing concerns about his oldest daughter, Sierra, Rex identifies adequate yearly academic growth, having friends, being labeled, and learning to communicate with peers and adults as his most significant needs. When describing his needs, Rex remarked:

So, the IEP was well established that speech was our focus and they did everything but speech. In her IEP, we tried to emphasize more speech-language intervention. But in the end the speech-language pathologist, there was, there was just kind of a wave where there wasn't a good speech-language pathologist, then there was a qualified one. However, she had a different take on what we should do for Sierra, so there was never really like a good intervention in the speech-language pathology area. (Rex, personal communication, June 24, 2017)

Diane. Diane lives in a rural, small town. She is a white 35-to 44-year-old female who is employed full time in an education-related field with a 4-year degree. Diane reports family income as \$90,000-\$99,000 range. Diane has three children currently living in the home; a fourth child, her oldest, recently moved out. All four of her children have or have had school-based services and IEPs. Willow, her oldest, is classified as Other Health Impaired. Maddison, her second oldest has Autism; her third child, Teri, is classified as Hearing Impaired. And the youngest, Beth, also has Autism. Diane spent most of her interview discussing the special education process as it related to her second

daughter, Maddison. Her concerns with Madison, including adequate socialization, having friends, employment skills, learning to communicate with peers and adults, being understood, and being meaningfully employed. Diane spoke with candor and openness when talking about her children and their disabilities:

My name is Diane, and my husband is Chuck. We have four kids. Our oldest is Willow, and she is 21. And all through school, super gifted and talented. Perfect grades, super social and all that kind of stuff. Things got trickier for her, just learned about her disability when she was a Junior. She was running crosscountry and collapsed on the side of the road, so hers is a physical Disability. It's Ehlers-Danlos syndrome so she just has loose joints and, so she just has to work out in a gym more so that her muscles will hold her joints in place because they don't work right. But that didn't have any real impact on school except for that she could no longer run and do some of the things that she loved to do, but that was fine. So then, she is 21 now.

So, Maddison is 17 now, and Maddison is where all the fun started for us. She was three months old, and she quit breathing, and we took her to the doctor. They did chest and ab x-rays, and we ended up with 13 broken ribs and a broken collarbone. They took her away on child abuse allegations. It took us three months to get her back home. And then, once we finally got her home, we got a referral to a neurologist because she was seven months and wasn't doing anything that a seven-month-old does. So, she was two and couldn't sit up, and three and couldn't walk. Four and didn't talk and so it all just played out. So, she was diagnosed for a long, long time with just as just developmentally delayed and other health impairment. We got a referral when we finally got her back home, so she was six months old. At nine months, we got a referral to a neurologist down at XXXX, and he referred us to Baby Watch at the time, so we started early intervention with her. So, for Maddison there is obviously lots that were off-kilter, lots without really great explanations and the beauty of the early intervention program is they didn't care about a diagnosis. They didn't care; they just were there to help her and to help us with her. She wasn't eating...we would try to feed her, and she would puke it back up. And so, we ended up with an OT [Occupational Therapist] because it was attention seeking and we didn't know. We were like, oh no and cleaned it up and so she would do it on purpose to get attention. Anyway, so we had an OT and a PT [Physical Therapist] and the speech-[language] pathologist. In the home, coordinator, you know the service coordinator, but then we also had like developmental [therapy] to teach you to play with your kids that have a disability. So, Maddison's diagnosis now is she got diagnosed as autistic at 13. She has a math processing disorder. She can do the math, but it is a slower speed, and it is like one point off intellectually disorder or ID. But, her, she is above-average intelligence and those kinds of pieces. So, she's confusing, you know, so she is one of the ones that is complicated because it is not clear cut as far as academics. So, she has always been mainstreamed since first grade, but they did pull her out for speech and pull her out for math. So, she has ADD; she is just attention deficit, she can get distracted over nothing. And then she has auditory processing. So, background noise complicates all of that. And then, she has bone issues, which we knew, we had broken bones when we were little with no great explanation. So, her diagnosis is Ehlers-Danlos because Ehlers-Danlos is a connective tissue disorder. And so, the older one, it's her tendons and ligaments and Maddison it's her bones, and so she actually will eventually go blind. She is losing; she has optic nerve drusen. She has calcium lesions in her optic nerves that have broken loose, and they bounce around, so she is losing sight, peripheral. So that is not super fun.

My Teri is twelve, and I am scared to death on where it goes because she has a profound hearing loss and auditory processing disorder and a cognitive memory disorder, so they describe that [learning for her is like] throwing mud and some of it will stick. So then, we just beat it [in] different ways. Like it must be visual and if we can make it tactile and Teri is in Resource. She works really hard and then because of the hearing thing; she's got lots she doesn't understand. She has a profound hearing loss in one ear, and the cognitive memory disorder just makes it impossible to memorize. But super social. But she is perfectionistic. Like that is just her little soul.

And then Sage is seven and autistic, and she is massive resource, and now it looks like she was not doing well the second half of first grade so now she has an aide for all core that happens in the classroom as well. So, she has an in-class one-on-one aide, Resource, and a teeny, tiny bit of mainstream. (Diane, personal communication, July 6, 2017)

Jennifer. Jennifer is a married 35-to 44-year white female. She has a husband, Don, and four children. They live in a suburban area within a large metropolitan city in a state located within the intermountain region of the U.S. Jennifer reports their income to be between 90,000 and 99,000 a year. Jennifer has a professional degree but is unemployed and not looking for work. Their oldest child, Luke, age 14, is diagnosed with a speech-language impairment, specifically a mixed expressive-receptive language disorder. Her concerns with Luke center around adequate socialization, having friends, being labeled, teased, and bullied, learning writing skills, and learning to communicate

with peers. To introduce herself, Jennifer said:

My name is Jennifer, my husband's Don. We have four kids, and our oldest is
Luke, and he's the one who has a language disorder. So, my next son is Skyler;
he's turned 12. I have a daughter who's nine, and then a son who's four. I'm from
the state of, my husband is from, and my oldest son, Luke was
born in a [New England state]. It was there that we identified that he was not
progressing along with his language development. And I had studied Linguistics,
that was my undergrad, and then I also got a Masters in Cognitive Experimental
Psychology.

And my emphasis was Language Acquisition and Phonological Acquisition, so I was familiar with the milestones I was looking for. I was looking for the various growing stages to see any kind comorbid development, but we didn't even get that far, because at age two to three, he was still communicating one-word utterances. And in addition to that, my husband and I both speak German fluently, so we were speaking German with him. And we were feeling that it wasn't because of that that he wasn't progressing in his language development. Because I had also tried baby sign with him—and that was just something I was doing because I had read that it helps to increase their communication before their fine motor skills and their articulators within the vocal tract catch up. So, it's easier to manipulate the hands than the articulators within the mouth. So, we tried that with him, and he just really didn't take to sign, either.

So, it was a language-based problem. It wasn't speech-based, but it was language-based. And Luke was no further in German than he was in English, so it wasn't as if—and we had taken our concerns to some doctors. But ultimately, we did a lot of researching and settled on some clinicians out of Vanderbilt University, and that's where we got a formal diagnosis when Luke was about to turn 4. (Jennifer, personal communication, July 1, 2017)

I clarified with Jennifer, Luke's diagnosis:

Well, back then—the DSM-IV has changed—but back then it was called Mixed Expressive-Receptive Language Disorder. So, they ruled out autism because that's one that commonly when a kid is not talking, they would want to. But he was so social, and he was interactive—he didn't interact with lots of people because he wasn't—when you can't understand. So, it wasn't just a receptive issue—an expressive issue because there are a lot of kids that are late talking, but they still understand everything. But he still was limited in how much language he understood. But he was very interactive with everybody that knew him, and they ruled out autism and considered what he had was Mixed Expressive Receptive Language Disorder. In the current DSM, they just call it Language Disorder. (Jennifer, personal communication, July 1, 2017)

I asked Jennifer how his current diagnosis, language disorder, is impacting him now as children with language disorders frequently present with disorganization, an inability to follow through due to a lack of understanding subtleties in the text, or struggle with comprehending complex and embedded sentence structures. They can also demonstrate an inability to follow multi-step directions. Jennifer begins talking about recent progress:

Yeah. So, he checks, and that's something that he did go through a process with seventh grade. Because having gone from a Montessori—and it's still a Montessori seventh-grade classroom, but it's Chartered. There are more traditional elements in seventh grade. They have like their online classroom, their Google classroom where they see assignments and what not. And he wants to do well in school, so he checks that kind of thing regularly. But he did—in the beginning, there was a lot of stuff that he was just missing. But the teachers in the school, they said, "Listen, it's not just Luke. It's a lot of kids, a lot of these seventh graders are just figuring out how to organize themselves." And so, I think in terms of self-organization, he can—something might slip here or there—but he's super conscientious. And he started off the seventh-grade year—he even had a D, but eventually, he was able to turn in some assignments and get that up to a C. But he had a lot of Cs, and maybe one B. And then his last two terms, he was getting A's and B's. And especially Math, he's really good at Math, and he struggles with language problems.

But, otherwise, he's doing great. Even things with multiple steps and what not, he does well. And he's not the kind of human calculator type. But his teacher said, "Luke, I know you can get a good grade. You just have to remember to turn your homework in," and she made this little—so we've had really good experiences, for the most part, with the teachers. There was one teacher, a science teacher that was not kind at all to him. Anyway, that was not positive. But we've, overall, had good experiences with his teachers, with the administrators, it's just the special ed. that we.... (Jennifer, personal communication, July 1, 2017)

Jennifer's voice trailed off. There was something about her special education process experience that she didn't want to communicate. And then, she started talking about Luke's dream:

...because he has grand plans to be a ski lift engineer. He loves to ski, and he did have a great kind of capstone project he had to do for seventh grade, so my

husband got him in to see this senior engineer at Doppelmayr USA, so they build ski lifts. So, the engineer took time with him, gave him a tour of the factory, and he does ultimately want to run his own ski resort. So, he has grand, grand plans. And I believe that he would get there, but there's no way around being able to be a little bit more fluent, and navigating social environments. Again, most people that spend time with him really come to love him, because they just know how sincere he is. And he just likes to ask lots of questions that maybe, somebody wouldn't ask you, because he just really wants to know everything about you. Anyway, I think he has a bright future, but I want to still support it however I can. Again, he's progressed on his own, and he doesn't have long. (Jennifer, personal communication, July 1, 2017)

Robin. Robin is a single 25- to 34-year-old white female with three children. The family lives in a rural area within the Intermountain Region of the Western U.S. She has a 2-year degree, but is unemployed and not looking for work. She reports yearly income between \$80,000 and \$89,000. Of her three children, one has an intellectual disability. The children attend public school. She is concerned about her child's yearly academic growth. Unfortunately, Robin participated in the survey portion of this investigation only; she moved from the Southwestern U.S. to the Intermountain Region. I repeatedly attempted to reach her via email and phone, but she did not respond to my attempts at contact. As such, only limited information, the survey results, is available from this participant.

Data Collection Techniques

In this section, I describe methods of data collection utilized in this investigation. There were three types of data collection. I utilized a 53-item survey to standardize the interview and to create a platform or springboard for further discussion during semistructured interviews. Second, I held a semistructured interview in a location and time of the participants choosing. In that interview, I utilized the survey responses to get

participants thinking and reflecting on their special education process experiences. Last, I discussed findings—the codes and themes developed from each participant's specific set of data with the participant.

Survey

I constructed a 53-item forced-choice survey to have my participants begin to think about and reflect on their special education experiences with their children and to provide categorical descriptors to interview responses. I designed the perceptually based and attitudinally-based survey questions with extensive assistance and borrowing from Duda et al. (2007), a document developed by Responsive Management, a nationally recognized research firm that conducts public opinion, perception, and attitudinal surveys. Interestingly and surprisingly, to create this investigation's survey, I utilized two perceptions, and attitude surveys found online. One was about litter in the community, and the other was about hunting. While this may seem unusual, I saw the potential in these surveys to create a similar survey about disability and related issues as the focus, rather than litter or hunting. As such, I utilized the same structure, format, pairing, and parsing of questions, basic sentence structure, tense, and parent-friendly language that were available in hunting about litter surveys.

The survey development guide provided by Duda et al. (2007) entitled Measuring Perceptions and Attitudes Toward Litter in Georgia's Local Communities provided the rationale for each type of question within the survey that I developed, and which was accessed by my 15 participants. For example, this manual provided definitions and examples for questioning and different question formats including, opinion, attitude,

awareness, knowledge, and behavior. The manual also provided clear guidelines and directions regarding voice, length, and content construction for an attitude or perception survey. Duda et al. (2007) stated:

There are several key guidelines for constructing a survey instrument. First, survey instruments should be written with a neutral perspective and without any preconceived ideas regarding expected or desired outcomes. Second, keep research objectives in the foreground of survey instrument development: use the minimum number of questions that will simply and directly fulfill the research objectives. Third, remember that the survey is being written for the target population, i.e., those responding to the questions. Avoid confusing language or content demanding prior, outside knowledge of a subject. Plan for the use of open-ended questions and questions with answer sets accordingly; note that open-ended questions primarily collect qualitative data, while closed-ended questions are usually concerned with quantitative data. Accommodate survey length to include a place at the end for collecting appropriate demographic information. After a suitable survey instrument has been drafted and pretested, data is ready to be collected. (pp. 16-17)

As an example, of how I utilized the Duda et al. (2007) litter survey and modified it to my own needs, I present the first litter question from the Georgia survey developed by Duda et al. and the first survey question in my investigation:

In your opinion, what are the most important quality of life issues facing Georgia today? (IF ASKED: "Quality of life issues" refer to issues affecting society.) (Open-ended; do not read list. Check all that apply.)

- 1. There are no important issues
- 2. Air quality-related issues (pollution, smog, etc.)
- 3. Crime
- 4. The economy
- 5. Education
- 6. The environment (non-specific) / pollution
- 7. Habitat loss / fragmentation
- 8. Healthcare
- 9. Immigration issues
- 10. Littering
- 11. Population growth
- 12. Recycling/waste management
- 13. Religious issues/lack of values

- 14. Transportation / roads
- 15. Urban sprawl / over-development / loss of green space
- 16. Water-related issues (quality, quantity, pollution, etc.)
- 17. Other (Enter other response.)
- 18. Don't know

For my survey, I took issues important and relevant to children with disabilities identified as concerns within the literature, and created question one to read like this:

Q1. In your opinion, what are the most important quality of life issues facing your son/daughter today? (You may indicate more than one response).

☐ There are no important issues
☐ Adequate socialization
☐ Having friends
☐ Being Labeled
☐ Being Teased
☐ Being bullied/cyber-bullied
☐ Moving to the next grade
☐ Learning to decode text in written language
☐ Learning to read
☐ Learning skills necessary to get a job
☐ Learning math skills
☐ Learning writing skills
☐ Learning to communicate with peers
☐ Learning to communicate with adults
☐ Being understood
☐ Being meaningfully employed
☐ Other

The resulting *Special Education Processes Survey* (Appendix 8) consists of 34 questions specific to perceptions and attitudes about special education within the participant's state, school, and community. The remaining 19 questions are strictly demographic—covering gender, age, income, employment, education, geographic location, family size, and the number of children with disabilities to provide a method of categorizing participant responses within the investigational findings. The survey has clear directions with simple categorical response options and ordinal scales. I placed the

survey on USU's portal to Qualtrics, a survey, research, data-collection site. Participants accessed the survey via a personalized link sent to them through their email accounts.

The survey provides a methodology for obtaining consistent data about their special education experiences. After taking the survey, some participants said that the survey needed a comment box. These participants wanted to explain their responses to many of the 34 perceptual and attitudinal questions. In each case that this occurred, I validated their need to explain but told them the interview was the vehicle to explain answers if necessary. As there are only 15 research participants, the obtained survey data is used primarily to categorize their initial perceptions, to establish the stability of their stated responses, and to establish credibility to the analyzed discourse, resultant codes, and developed themes. I also utilized surveys as an assistance tool to help guide or move the interview forward. I note here that many of the survey questions brought deep reflection in participant interview responses. Frequency counts and percentage of occurrence are the only type of statistical presentation that I utilize for the data from these 15 participants.

Interviews

I held eight interviews in the participant's home, one at the child's school, three in a neutral location of the participant's choosing, one via Skype, and one via phone when the participant and I gave up on Skype due to a repeatedly poor connection. Before the interviews, I told participants that I would choose pseudonyms for them, their partners, their children, and refer to school personnel, schools, districts and states through general terms or by general size and general location.

Following the interview, I informed my chosen CITI certified transcription company that the transcriptionist was to redact and replace names and locations with general terminology (e.g., Child 1, School A, District 2). I asked them to purposefully omit these items from the transcript to ensure participant confidentiality. I created pseudonyms following receipt of the transcriptions. Schools, parents, the children with disabilities, district representatives, and outside professionals received fictive names, or I used titles, ensuring confidentiality of the children with disabilities.

For each interview, I used open-ended questions about specific aspects of parents' perceptions regarding the special education process and the way school professionals say things or talk to them. As a tool during the interview, I utilized individual participant responses from the survey as a point of reference for the questions. I also created a list of Potential Interview Questions (Appendix 9) that were open-ended questions to assist the process as well, if needed. I utilized these two sources on occasion to get parents talking again when it appeared that the interview was stalling, or the participant was starting to respond circularly (talking about things already mentioned). The interviews ranged from 36 minutes to 1 hour and 5 minutes. Creswell (2009) suggested digitally recording interviews. I recorded the interviews digitally on a Microsoft Surface Pro 3 with Windows 10 using the voice recorder feature of that package, a Microsoft Windows 10 cell phone with the same voice recorder, and a Sony IC digital recorder with multidirectional speakers. I used three recording devices in case one or more failed during the interview, or if background noise was present. Three devices also gave me the option to choose the file with the best audio gain. I labeled the digital files with the interview date

and a participant number so that no identifiers were present. I sent the digital file to a transcription service via a secure upload website that the company provides. I took notes during each interview to aid my memory when coding the data (Creswell, 2009).

Data Analysis Procedures

In the following sections, I discuss my data analysis procedures for this investigation. I discuss grounded theory, critical ethnography, multiple case study design, and discourse analysis.

Grounded theory. Strauss and Corbin (1998) describe a theory as "a set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena (p.15)." These researchers further suggest that by conducting a grounded theory study, one "does not begin a project with a preconceived theory in mind...Rather, the researcher begins with an area of study and allows the theory to emerge from the data (Strauss & Corbin, 1998, p. 12). As such, there is no a priori theory specific to this investigation. Rather, I allowed the data to drive the theory. Grounded theory, then, is a "qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in the study" (Stauss & Corbin, 1998, p. 13). To engage in grounded theory research, Charmaz (2006) suggests multiple stages of data collection as well as the continued refinement and development of interrelationships of categories of information.

Creswell (2009) writes that there are two key characteristics of this strategy of inquiry, including the "constant comparison of data with emerging categories" and

"theoretical sampling of different groups to maximize the similarities and differences of information" (p. 15). In this investigation, I obtained consent and participation from fifteen participants' (cases) to allow for within and across participant comparison as emerging codes and categories arose. Comparison of these cases allowed me to maximize any similarities and differences.

In discussing Strauss and Corbin (1998), Harry, Sturges, and Klinger (2005) write that step one of the grounded theory analytic process is to engage in the process of constant comparison. By following this methodology, I coded an incident and "compare[d] it with all previous incidents so coded" (p. 5). By engaging in this process, I generated "theoretical properties of [a] category" (Strauss & Corbin, 1998, p. 106). Harry et al. also write that step two is "to group the discrete codes according to conceptual categories that reflect commonalities among codes" (p. 5). Strauss and Corbin refer to step two as axial coding, meaning that one assembles codes around "axes" or categories. Harry et al. (2005) state that as "categorizing/axial coding" is occurring, "the interpretive lens of the researcher...is... beginning to abstract meaning from the data" (p. 5). In the third step of the analytic process of grounded theory, I developed "themes" (Harry et al., 2005), "referring to the underlying message or stories of these categories" (p. 5). As a theme developed, "theory development" became "a recursive search for consistency and logic" (Strauss & Corbin, 1998, p. 156). Refinement of themes, the final stage of the analytic process of grounded theory, occurs as "negative cases" and "poorly developed categories" were examined so that variation was accounted for and explained (Harry et al., 2005, p. 5).

Critical ethnography. In addition to utilizing grounded theory as my theoretical standpoint, I utilized methodology consistent with critical ethnography. A critical ethnographer studies "social issues of power, empowerment, inequality, inequity, dominance, repression, hegemony, and victimization" (Creswell, 2012, p. 467). Importantly, as a critical ethnographer, I positioned myself in the text, being reflexive, self-aware of my role, and disclosed biases and values (Creswell, 2012). While this was a non-neutral position, it allowed me to advocate, as necessary, for the emancipation of marginalized parents and their children with disabilities within the current special education system. Also, importantly, in critical ethnography, "data collection" was "less focused on time in the field or on the extent of data and more on the active collaboration between the research and the participants during the study" (Creswell, 2012, p. 478). Moreover, because critical ethnography may bring change that affects the lives of participants, "the participants need[ed] to be involved in learning about themselves" (Creswell, 2012, p. 478). The participants also needed to learn the steps needed "to be taken to improve their equity, to provide empowerment, or to lessen their oppression" (Creswell, 2012, p. 478). The interview questions explored reflectively their attitudes, feelings, and beliefs as well as what they know and understand about the special education process; these questions also explored attitudes, feelings, and beliefs reflexively as well as what they did not know and did not understand about the special education process. As part of that reflexive process, I engaged in advocacy and education to reduce issues of marginalization or disempowerment. This engaged positionality aligned with the social justice component of CDT; it was a method for providing dignity

to parents and their children with disabilities (Mažeikienė & Ruškė, 2011).

Multiple case study design. A second methodology that I utilized in this investigation was the use of multiple or repeated case study design. This methodology was consistent with and an appropriate tool for the grounded theory lens. Through this methodology, I focused on "developing an in-depth understanding" (Creswell, 2012) of the special education process via the perspective of fifteen parents of children with disabilities who were currently engaged in or who had gone through the special education process. Yin (2003) writes, referencing multiple case design:

Each individual case study consists of a "whole" study, in which one seeks convergent regarding the facts and conclusions for the case; each case's conclusions are then considered to be the information needing replication by other individual cases. Both the individual cases and the multiple-case results can and should be the focus of a summary report. For each individual case, the report should indicate how and why a particular proposition was demonstrated (or not demonstrated). Across cases, the report should indicate the extent of the replication logic and why certain cases were predicated to have certain results, whereas other cases, if any, were predicated to have contrasting results. (p. 59)

I utilized this logic and methodology of multiple case design within and across cases when engaged in critical discourse analysis and the resultant development of themes and codes that arise from the data.

Discourse analysis. As defined in the initial section of the paper, discourse, as S. Hall (2001) writes in referring to Foucault's explanation:

Defines and produces the objects of our knowledge. It governs the way that a topic can be meaningfully talked and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others. Just as a discourse 'rules in' certain ways of talking about a topic, defining an acceptable and intelligible way to talk, write, or conduct oneself, so also, by definition, it 'rules out', limits and restricts other ways of talking, of conducting ourselves in relation to the topic or constructing knowledge about it. (p.72)

In CDA, then, language is a social practice (Fairclough & Wodak, 1997) and the context of language use is crucial. To enrich the above definition of discourse, Fairclough and Wodak write for those practice CDA, discourse—language use in speech and writing—is:

...a form of 'social practice.' Describing discourse as social practice implies a dialectical relationship between a particular discursive event and the situation(s), institution(s) and social structure(s), which frame it: The discursive event is shaped by them, but it also shapes them. That is, discourse is socially constitutive as well as socially conditioned—it constitutes situations, objects of knowledge, and the social identities of and relationships between people and groups of people. It is constitutive both in the sense that it helps to sustain and reproduce the social status quo and in the sense that it contributes to transforming it. Since discourse is so socially consequential, it gives rise to important issues of power. Discursive practices may have major ideological effects—that is, they can help produce and reproduce unequal power relations between (for instance) social classes, women and men, and ethnic/cultural majorities and minorities through the ways in which they represent things and position people. (p. 258)

Thus, by implementing CDA, discourses were viewed as a "relatively stable uses of language serving the organization and structuring social life" (Wodak & Meyer, 2009, p. 6). In summary, then, CDA, is "the study of meaningful language units larger than a sentence which sheds light on the social meaning of discourses" (Avissar et al., 2016, p. 975; Van Dijk, 2011). Furthermore, with CDA as my chosen methodology, I not only view language as a form of social practice (Fairclough & Wodak, 1997) but it "focuses on the ways social and political domination are reproduced in text and talk" (Avissar et al., 2016, p. 975). Likewise, in referring to Foucault (1975) and Giddens (1984), Wodak and Meyer (p. 9) articulate that in CDA, "power is seen as a systemic and constitutive element/characteristic of society (e.g., from very different angles)."

As discourses function to maintain what does and doesn't get said and known, by

practicing CDA, I was:

...fundamentally interested in analyzing opaque as well as transparent structural relationships of dominance, discrimination, power, and control as manifested in language. In other words, the goal of those who practice CDA aim "to investigate critically social inequality as it is expressed, constituted, legitimized, and so on, by language use (or in discourse). (Wodak & Meyer, 2009, p. 10)

Fairclough and Wodak (1997, pp. 271-280) summarize the tenets of CDA: first, CDA addresses social problems; second, power relations are discursive; third, discourse constitutes society and culture; fourth, discourse does ideological work; fifth, discourse is historical; sixth, the link between text and society is mediated; seventh, discourse analysis is interpretive and explanatory; and eighth, discourse is a form of social action.

Relating Grounded Theory and Critical Discourse Analysis

Fairclough and Holes (1995) developed a multi-level framework for studying discourse. These researchers combined micro-, meso-, and macro-level interpretation.

First, one considers the micro-level; one examines the text's syntax, metaphoric structure, and rhetoric. At the second level, the meso level, one studies the text by revealing power relations and determining how they act. At the third level, one seeks to decipher the intertextual understanding. That is "one tries to recognize the societal currents that are affecting the discourse being studied" (Avissar et al., 2016, p. Thus, by CDA, one aims to reveal unequal power relationships that may exist between different stakeholders and policymakers (Liasidou 2011; Van Dijk 2011). This method that refers to CDA as just described is not unlike the process of grounded theory in which "we learn how our research participants make sense of their experiences" (Charmaz, 2014, p. 19). As we do

this in grounded theory, Charmaz stated, "we begin to make analytic sense of their meanings and actions" (p. 19). Moreover, the analytic steps of grounded theory (described above) pair well with CDA. At the micro level of grounded theory, one codes an incident and begins comparing it other incidences so coded to generate a category (Charmaz, 2014; Strauss & Corbin, 1998). At the meso level of grounded theory, one looks for relationships around the codes. Charmaz calls this "focused coding and categorizing" (p. 18) just as in CDA, in which one focusses on *Power* Relationships. Last, at the macro level of grounded theory, theory building is taking place, just as in CDA where one tries to decipher the intertextual relationships to decipher meaning.

Analysis

As previously noted, my standpoint for this study was grounded theory; I conducted an *a priori* investigation. The intent was to uncover codes, themes, and discover relationships in the data without trying to fit it to a given theory, such as CDT. As such, following the recorded interviews, I sent the electronic mp4 audio file via a secure site to *SameDay Transcripts*, a CITI certified, FERPA compliant, transcription company. Transcription turnaround was typically 24 to 48 hours depending on file size. Once I received the transcripts from the transcription company, I reviewed them line-by-line while listening to the audio recording. I reconciled discrepancies through multiple playbacks. Transcriptionists marked unintelligible sections with times from the audio file. I attempted to decipher the missing information in each case—most often, but not always successfully.

Following transcription, I uploaded the transcripts into Nvivo11, a qualitative

software program. I utilized this program as a data-collection and coding assistant. With Nvivo11, I established codes and definitions of codes. I defined codes as they emerged and coded participant responses into units of data that aligned with CDA and the research questions, developing themes (Foss & Waters, 2007). To ensure that code drift did not occur, I compared data, codes, and definitions (Creswell, 2009). I checked for relationships between codes and cases and identified themes that related to the openended questions. From this process, I established theoretical assumptions from the data specific to this investigation (Foss & Waters, 2007).

Quality Criteria

To judge the quality of qualitative research, Guba and Lincoln (1989) provide suggestions. As I approached this investigation from a grounded theory standpoint with the application of methodological tools consistent with critical ethnography, it was important to select a set of quality criteria that compliments these needs. As my short-term goal was to support and emancipate marginalized parents and their children with disabilities within the current special education system, I considered it appropriate to ensure that this dissertation research satisfies the quality criteria associated with trustworthiness, authenticity, and credibility (Yin, 2003).

Trustworthiness. To establish trustworthiness—the judgment of goodness that comes from reviewing the quality of qualitative investigations—Lincoln and Guba (1985) provided four considerations. Is the research credible, transferable, dependable, and can it be confirmed? (Lincoln & Guba, 1985). While conducting this investigation, I considered these questions repeatedly as I reflected on the process of qualitative investigation and

the discourse data that surrounded me.

Credibility. *Truth value* is the essence of credibility (Lincoln & Guba, 1985). One establishes truth value or credibility by creating confidence in the research findings between the participants one studies and the context (Lincoln & Guba, 1985). To establish confidence means that I must work to convince that the research findings and interpretation are convincing to the reader and my research participants (Lincoln & Guba, 1985). I used the following strategies to ensure credibility of this dissertation research: persistent observation,

Prolonged engagement. Prolonged engagement provides scope: it is the "process of building trust and rapport with informants to foster rich, detailed responses" (Cope, 2014, p. 90; Lincoln & Guba, 1985). To promote this process, I allowed adequate time in collecting data (both survey and interview). I explained to participants that I wanted them to consider their responses to the survey questions in preparation for the interview, to reflect on their responses, and to think of or consider examples for questions survey questions that needed a "comment box" to provide background and understanding. This process assisted many of my parents. Several commented that they appreciated the time between the survey and the interview to think about and reflect on their special education experience. They reported that the interview was more straightforward than they had expected. I purposefully created a relaxed interview. Participants had adequate time to process survey responses through reflection, to respond to questions, and to revisit comments made during the interview. This pace allowed deep, rich understanding and thick, complete themes to develop naturally.

Persistent observation. Persistent observation provides depth to a study: it concerns my attention as a researcher to the feelings or emotions of my participants while studying their discourse. (Lincoln & Guba, 1985). As such, when I engaged with my participants, I practiced persistent observation. That is, I listened for themes through their examples, discourse, tone, posture, and openness. If I noted that information began repeating itself, I knew that it was time to wrap the question (or line of questions) up and begin to explore a new topic.

Peer debriefing. Lincoln and Guba (1985) noted that one method of addressing credibility is to have a sound, convincing argument for both the research participants and the intended audience. Peer debriefing is the discussion of the research—including the findings, conclusions, analysis, and hypotheses—with a disinterested peer (Lincoln & Guba, 1985; Mertens, 1998). Being able to explain one's research to a colleague and at the same time discuss dilemmas, problems, themes, results, arguments, and conclusions can be an effective way to share and validate descriptions and process the analyses (Schwandt, 2001). To accomplish this goal, I enlisted the assistance of three colleagues. The first colleague was a quantitative academic who is highly skeptical of qualitative inquiry. During our exchanges, he would ask many questions about my line of thinking until it made sense. It has been my perception that if I can make it clear to this colleague, then I am doing well with credibility. The second colleague was a qualitative researcher and Ed.D. candidate who is conducting a similar inquiry to my investigation, specifically parent perceptions of transition services for students with intellectual disability. As she understands my topic, the qualitative-investigative process, and as we have read and

reviewed similar research, this individual became an ideal sounding board to address themes, codes, and conclusions. The third colleague was my dissertation chair. We met regularly and discussed matters as he reviewed work or if concerns, problems, or issues arose. We connected through Skype, email, and in person.

Member checking. One critical element of credibility is the confirmability of results. Member checking is now considered an accepted and often expected practice to help achieve that result (Charmaz, 2014). Typically, member checking is accomplished by returning to the participants and reviewing with them participant specific descriptions, the critical themes, and the case analysis (Charmaz, 2014; Creswell, 2009). I accomplished member checking through two methods: first, I performed member checking online, during the interview. In other words, I prompted the participant for clarification or more detail (e.g., You said, "...."; did you mean? "Can you provide an example, so the listener and I can understand better? Some of my participants have said, "...."; do you agree? Or do you see it differently? Can you explain more?) The second method of member checking, the traditional approach, was also conducted. That is, once the coding, relationships, and theme development were complete, I reviewed with each participant their specific descriptions, the critical themes that emerged from their case, and my overall analysis of their case and the investigation. With each member check session, I asked them to report whether they felt that the description, themes, and analysis were accurate. (Creswell, 2009). With each participant, I spent 10 to 15 minutes of time reviewing the themes uncovered in this dissertation and the themes concerning their communications with me (interviews). In each case (n = 14), participants acknowledged

and agreed with developed themes. Additionally, they expressed appreciation for this dissertation project and the chance to be heard. An audit trail provides evidence of member checking that I utilized to document this investigation.

Triangulation. Yin (2014) describes triangulation as "the convergence of data from different sources, to determine consistency of a finding" (p. 241). In this investigation, the convergence of data occurred using a multiple case design and grounded theory. I engaged in a constant comparison of codes and themes as they emerged within and between cases. Documents to achieve triangulation and constant comparison included surveys from fifteen participants and transcripts from open-ended, semistructured interviews of 14 participants, and member checking within interviews and following interviews.

Resonance. Resonance refers to the ability of work to "meaningfully reverberate and affect an audience" (Tracy, 2010). There is potential for this research to transform the emotional dispositions of my intended audience and promote greater mutual regard for parents and their children with disabilities. This charge is known as *empathic validity* (Dadds, 2008). I hope that readers will experience emphatic validity and see my work as authentic and transferable. As such, I, as a researcher and writer, attempted to engage in practices that promote empathy, identification, and reverberation of this research with my intended audience who may or may not have direct experience with my topic (Tracy, 2010).

A key path according to Tracy (2010) in achieving "resonance and impact is aesthetic merit" in which the text for the reader is presented in "a beautiful, evocative,

and artistic way" (p. 845). The second method to achieve resonance, *transferability*, is akin to external validity (Lincoln & Guba, 1985). Tracy notes that "*transferability* is achieved when readers feel as though the story of the research overlaps with their own situation and they intuitively transfer the research to their own action" (p. 845). To accomplish both aesthetic merit and transferability, throughout the results, I have attempted to provide *thick*, rich descriptions so that reader will gauge for themselves whether this research may apply to their situation. This attempt at transferability includes an extensive and careful description of the participants, their demographics, their concerns, and the culture surrounding children with disabilities within the special education process. In other words, I have taken care to carefully describe the phenomenon I am studying (Mertens, 1998).

Dependability. Lincoln and Guba (1985) suggest that good qualitative research is dependable. The term *dependability* is a way of documenting the process of inquiry to ensure thorough and high-quality research. Paper or digital trails typically accomplish a dependability audit (Mertens, 1998). For this dissertation research, that meant maintaining a case-study protocol that detailed each step of the research process (i.e., the dissertation proposal), this was followed by Institutional Review Board documentation and review, and letters of cooperation and contract agreement between the cooperating district and this researcher.

Confirmability. The quality criterion confirmability is parallel to objectivity (Guba & Lincoln, 1989) in quantitative inquiry. A confirmability audit is necessary to trace data back to their sources as well as to verify proper enactment of prescribed

methodologies for accurate data synthesis (Guba & Lincoln, 1989). I synthesized the data for this investigation via Nvivo11, a qualitative software program, in which a file of the data, its sources, codes, themes, and relationships are synthesized and maintained. As such, this information is available should a confirmability audit be needed in the future.

Authenticity

Apart from trustworthiness and its underlying concepts which define issues of methodological rigor in qualitative research (discussed above) is the concept of authenticity. "Authenticity refers to the ability and extent to which the researcher expresses the feelings and emotions of the participant's experiences in a faithful manner" (Polit & Beck, 2012, as cited by Cope, 2014, p. 89). Guba and Lincoln (1989) and Schwandt, Lincoln, and Guba (2007) state that authenticity has five criteria, including fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity.

Fairness. Fairness, according to Schwandt et al. (2007) is a "balanced view that presents all constructions and the values that undergird them" (p. 20). In other words, the research presents all value differences, views and conflicts. It is achieved through a two-part process (Schwandt et al., 2007): first, the researcher provides fairness (or justice) by presenting different values and beliefs "represented by conflict over issue" (p. 20). These researchers argue that this process is of value during data collection and analysis (Lincoln & Guba, 1985). Second, Lincoln and Guba suggest that the second step to fairness is negotiation. An example of this is when a researcher seeks informed consent from a research participant. To be fair would be to solicit informed consent throughout the

process. Guba and Lincoln (1989) and Schwandt et al. state that fairness requires constant use of the member-check process. In discussing this last step, Schwandt et al. wrote:

...the member-check process...includes calls for comments on fairness, and which is utilized both during and after the inquiry process itself (in the data collection-analysis-construction stage and later when case studies are being developed. Vigilant and assiduous use of member-checking should build confidence in individuals and groups and should lead to a pervasive judgment about the extent to which fairness exists. (p. 22)

This concept of fairness is akin to ethics, standards of conduct based on moral principles. In this investigation, I engaged in fairness and ethical practices by committing to several practices. First, I submitted a proposal along with English and Spanish letters of informed consent (Appendices 6 and 7) and recruitment flyers (Appendices 4 and 5). I also submitted a *Statement of Transcription Security* (Appendix 10), the *Special Education Processes Survey* (Appendix 8), and Potential Interview Questions (Appendix 9) to the USU Institutional Review Board (IRB). Upon conditional approval, I obtained a letter of cooperation from a district and submitted that document to the IRB for review (Appendix 3). After receiving full approval from the IRB, I submitted that letter to the school district and began negotiating with the director of special programs and the technology director about a notice for parents within their newsletter in both English and Spanish. As participant recruitment started, I met with each potential participant, either by telephone or through email to explain the purpose of the study, anonymity, and how the data generated and collected during the investigation would be used.

Each participant electronically signed a *Letter of Informed Consent* (Appendix 6) acknowledging the voluntary nature of this investigation and participation. I practiced fairness by not pressuring participants to complete the study. I called or emailed and gave

them a kind reminder if participation (the survey) had not begun after a week. I allowed participants to choose the location of the interview so that they would be comfortable. I worked around their schedule so that participation would be financially fair. During the interviews, I reminded participants that they could refuse to answer or end the meeting at any time and request that I destroy their information. I practiced member checking with my participants during data collection and after completion. I also used pseudonyms as I presented interpretations of the data as research findings. Last, a copy of the study's findings will be available for each participant to review.

Ontological and educative authenticity. Schwandt et al. (2007) refer to ontological authenticity as the process where "an individual's (or groups') conscious experience of the world became more informed and sophisticated" (p. 22). These researchers note that if each person's reality is constructed and reconstructed as that person gains experience, interacts with others, and deals with the consequences of various personal actions and beliefs, "an appropriate criterion to apply is that of improvement in the individual's (and group's) conscious experiencing of the world" (p. 22).

Educative authenticity, on the other hand, refers to "a raised level of awareness" (Tracy, 2010, p. 840). As such, participants or stakeholders in an inquiry develop greater understanding and appreciation of the constructions of others (Schwandt, 2001). With that said, Schwandt et al. (2007) wrote:

It is not enough that the actors in some contexts achieve, individually, more sophisticated or mature constructions, or those that are more ontologically authentic. It is also essential that they come to appreciate (apprehend, discern, understand)—not necessarily like or agree with—the constructions that are made by others and to understand how those constructions are rooted in the different value systems of those others. In this process, it is not inconceivable that

accommodations, whether political, strategic, value-based or even just pragmatic, can be forged. But whether or not that happens is not at issue here; what the criterion of educative validity implies is increased understanding of (including possibly a sharing, or sympathy with) the whats and whys of various expressed construction. (pp. 22-23)

Action. As my research standpoint is grounded theory utilizing tools of critical ethnography, it was essential that I engaged with participants. It allowed me to assist in "empowerment, emancipation, anticipated and hoped for social transformation, particularly toward more equity and justice" (Guba & Lincoln, 2005, p. 198). This reflexive engagement, after all, was an end goal. As such, during the interviews and member checking practices, I practiced ontological and educative authenticity with my participants (Guba & Lincoln, 2005, p. 207). That is, I acted to create a "raised level of awareness" (Schwandt et al., 2007, p. 23) to "construct and reconstruct their knowledge" (p. 22). For example, I advocated for the participants' children by informing parents of their rights when they weren't sure, and I coached several participants on how to approach to request additional support. For example, Rebecca said after coaching, "And I didn't know that I could even push for that" (Rebecca, personal communication, June 7, 2017). As another example, Sandy stated after coaching, "You're talking about speech and more time. I actually don't feel comfortable asking for more. So, I feel like I would be a burden to have to call everyone back together but it's my daughter so to heck with them" (Sandy, personal communication, April 6, 2017).

The second form of ontological and educative authenticity is to engage with the professionals and team members who surround my participants. (Guba & Lincoln, 2005). It is my long-term goal to interact with these individuals through publication,

communication, and training. Through the data collection (surveying and interviewing), coding, member checking, and theme development, I have identified six areas that require action. It is my goal to inform, train, coach, and advance a plan for change (Creswell, 2012). It is my goal to report the data as a "call to action" to address instances of hegemony and inequity in special education. Included in which will be a specific plan of action for change based on these findings, and I will discuss how I, and those I investigate, changed (Creswell, 2012, p. 479).

Control. By engaging ontological and educative authenticity as a methodological tool, I desire to not only create a "raised level of awareness" (Guba & Lincoln, 2005, p. 207) for all involved parties but to further that awareness. This awareness will help members of the community "take control of their futures" (Guba & Lincoln, 2005, p. 202). Individuals can begin changing practices to lessening/halt hegemonic discourse and practices. Likewise, I desire to have the research participants, "take control of their futures" (Guba & Lincoln, 2005, p. 202). I want parents to be empowered or feel emancipated when they experience hegemony in the context of special education meetings. As such, as I engaged with participants, I encouraged them to continue to advocate for their children with disabilities to ensure that their children were receiving a Free Appropriate Public Education.

Catalytic and tactical authenticity. Catalytic authenticity refers to the extent to which action is stimulated by the inquiry process (Schwandt et al., 2007) while tactical authenticity refers to the extent to which participants within the research project are empowered to act (Schwandt et al., 2007). It is my goal to give participants a copy of the

final dissertation report to encourage catalytic and tactical authenticity of this research. I plan to invite them to participate in a project debriefing and determine at that time if they are compelled to act on their new knowledge.

Consideration of Possible Ethical Issues

The parents of children with disabilities who participated in this research may have occasionally felt uncomfortable sharing their stories about the special education process and children with disabilities. Participants knew and could exercise their right to refrain from answering questions at any time, but that never became the case; I accommodated participant needs by offering neutral locations to meet. I strived to make accommodations that would provide a pleasant and positive interview setting. I respected their homes through simple gestures like taking off shoes before entering. I acknowledged and validated the participants' stories, and shared my own experiences with them. I avoided at all cost, loss of confidentiality and anonymity by providing participants with pseudonyms and identifying only generalities about their location, district, and school; I referred to school personnel by title only. I also took great pains to work around the participants' schedules to avoid economic and social loss. Ahead of time, I let them know that if there was a question that made them uncomfortable, they could just decline to answer without repercussions to avoid psychological or physical harm. I did not collect or keep any sensitive data. With each audio recording, I requested from SameDay Transcripts to redact any sensitive or confidential information, such as locations, titles, individuals, schools, districts, and state. I reported progress with my doctoral committee Chair on a regularly scheduled basis and sent him samples of

transcripts to review. Meetings occurred via Skype, phone, and email.

Potential Validity Threats

I examined the discourses of parents who have children with disabilities surrounding the special education processes that they experienced in a state located in the Southwestern U.S. and one within the intermountain region. As such, these results are specific to that context. Also, most of the participants within this research project were White except for one who identified as "Other." Findings are only transferable to school districts that are of similar size with similar special education process practices.

Nevertheless, as described throughout this body of work, the concerns and problems parents identified are problems that have been described throughout the literature for the past forty-five years, in a multitude of different contexts (including cultural and linguistic diversity, inclusion, transition, and disability category). Even so, generalizations concerning the discourse parents and children with disabilities encounter as they interact with professionals from variant geographical areas, languages other than English, ethnicities other than Caucasian, or from different levels of SES may be divergent from the results of this study.

Another potential threat to the validity of this investigation is the length of study.

A short-term study such as this investigation is a snapshot, a moment in time. It can identify the discourses that parents of children with disabilities experienced in the past, but it cannot predict the discourses that these parents with disabilities will experience in the future. With training and awareness from professionals on the issues within this investigation, there exists the possibility if an environment that they could experience that

is void of hegemonic practices that lead to marginalization.

Last, I acknowledge my positionality as a researcher. It may have affected part of the results of this study as I engaged with participants and was reflexive in their discourse.

How I Dealt with the Potential Validity Threats

To deal with the potential validity threats identified above, I carefully described participants by providing extensive demographic background data. I also utilized a survey to validate participant responses. I frequently used member checking as a tool to ensure authenticity, consistency, confirmability, and transferability of results. I also acknowledge my positionality and bias as a researcher: my short-term goal to emancipate the marginalized voice of parents who have children with disabilities within the context of the special education process. But as I consider the results and the frustrations of these 14 parent participants, I would not change that objective as these parents need more support, more understanding, and more acknowledgment, and more credit.

Chapter Summary

In this chapter, I detailed the research methodology I used to explore the perceptions of parents who have children with disabilities as they discussed the special education process. The purpose of this study was to develop a grounded theory that describes and explains the discourses within the special education process of public education. Ethnography and critical ethnography methodologies as well as the use of

multiple case study design guided efforts to collect and examine data strategically while providing the opportunity to support and empower parents of children with disabilities, which did occur throughout the investigation. For this research project, I collected survey data that I utilize to guide the semistructured interview and to develop rich, thick themes. I chose to combine critical discourse analysis with the grounded theory analytic process to ensure a rigorous data analysis process.

CHAPTER IV

SURVEY FINDINGS

Overview

This chapter is part one of three findings chapters of this investigation. In this chapter, I begin to answer the main research question through survey data collected during this investigation. I document the voice of fifteen parents who have children with disabilities (n = 15). These parent participants responded to 34 survey questions by completing an online survey posted on the research website, *Qualtrics*, utilized by Utah State University. These 34 perceptions- and attitudes-based research questions provide an avenue for their voice through "forced-choice" categorical response opportunities. I establish that there exist clear and genuine concerns held by parents who have children with disabilities, particularly as they engage in and interact with the special education process.

I first show fears participants expressed. They all have *quality of life concerns* for their children with disabilities. Most are concerned about their child's ability to socialize and to communicate with peers and adults. Interestingly, my participants were less concerned with their child's quality of life in the school and more concerned about their child's ability to function at home and in the community. I also show how they might handle those concerns; many participants stated that they would plan with the school and even more indicate that they would seek outside services. I present how participants are either not seeing the benefit of specialized instruction or they do not see sufficient

progress and want more for their children than the school is willing or able to provide.

Also in this chapter, I present the participants' perceptions about obtaining support. In general, participants indicate a perceived difference in the ability to communicate with their child's teacher and with that of evaluation review/IEP team member participants. Two interesting developments from this data are that most participants reported feeling like they could speak their mind in both situations. However, communication with the teacher was more productive than with special education staff; a higher proportion of participants reported that special education team communication was 'not productive.'

Additionally, I present participants' attitudes about special education issues. Participants responded to questions about having a child with a disability versus seeing a child with a disability. They were also asked to put themselves in someone else's shoes and take on an "other's" perspective. Responses to this question drew a direct relationship to participants' attitudes about labels uncovered in the interviews; this will be discussed thoroughly in Chapter V, *Interview Findings*. Attitude questions also addressed the participants' view of the cost of specialized instruction and contrasted it to the equity of children receiving specialized instruction support. The data indicates that while participants are unclear about funding, they are clear that specialized instruction has its place and is of value to children with disabilities who require access to extra support.

Last, I present concepts of power as addressed by participants through categorical responses. Participants responded to questions addressing power as repression, power as a social relation, and power as being productive. While most participants indicated that

they felt they had the same voice, say, or authority in an evaluation review meeting or IEP meeting, some participants indicated that they felt like they did not have the same power. They felt repressed, their voice unheard, and they did most of the listening.

Responses to these questions draw a direct relationship to participants' discussions during the interview and their comments about feeling unheard.

In the following chapter, Chapter V, I present findings to 14 semistructured interviews (n = 14) that occurred after the surveys. In each case, I drew from the participants' survey responses to assist the interview, but not lead it. I wanted participants to have the opportunity to explain and discuss issues that may have diverged from the literature so that the reader could be informed. The survey, as indicated by several participants, got them thinking about their experiences; they reported feeling more prepared with more organized thoughts at the time of the interview. As such, in Chapter V, I document remarkably consistent codes, themes, and relationships that are within the deep, rich texts my investigation's participants. I present a word map of their perceptions, and I discuss the themes Power, Advocacy, Equity and Equality, Dignity, and Voice which my participants revealed through the interviews. The theme *Power* emerged from discourses coded as Power via Communication, Procedure, Lack of Knowledge, Expertise, Lack of Procedural Knowledge, Personal Agenda, Experience, Number, Authority, Working Relationships, and Power Gained through Knowledge. I present these aspects of power relating to Foucault (2003) in which he defined power as is repression, a social relation, and an object of productivity.

In the remaining Findings chapter, Chapter VI, I present the participants'

concluding thoughts on the special education process and their wishes.

Perception Survey Questions

With the demographic responses in mind, I turn to the perception survey questions of this investigation. Participants responded to 34 questions about their perceptions, perceived perceptions of others, and attitudes that speak to having a child or children with an identified disability.

Quality of life. The first two questions of the 53-item survey are specific to the participant's perceptions of their child with disabilities regarding quality of life issues and what she or he she might do to help their child achieve those outcomes. In discussing Friedman (2005) and Hogan and Murphey (2002), Moore (2012) argued that "all effective endeavors are based on a clear understanding of the outcomes that are being sought. Without such an understanding, one's efforts are less focused and less effective" (p. 7). In considering outcomes for children with disabilities, Moore noted a shift in thinking from "terms of *developing capabilities* (rather than 'reaching potential'), *meaningful participation* (as opposed to social exclusion or marginalization)" and the consideration of a "quality of life." (p. 7).

In thinking about these terms, Sen (2005) considered capabilities as the opportunity to achieve valuable combinations of human functioning—what a person can do or be. Similarly, Nussbaum (2011) wrote that simple questions surround capabilities: simple question: What are people able to do and to be? What real opportunities are available to them? To Nussbaum (2011), capabilities are "not just abilities residing inside a person, but also the freedoms or opportunities created by a combination of personal abilities and the

political, social and economic environment" (p. 20).

Moore (2012) stated that the reason children need to develop functional capabilities—including children with disabilities (in other words, *all* children)—is to "participate meaningfully in all aspects of their lives" (p. 8). Moore also noted that according to the World Health Organization's (WHO, 2001) *International Classification of Functioning, Health, and Disability*, participation is defined as "involvement in a life situation" (p. 10). Moore writes:

Why *meaningful* participation? Participation is more than being present in different environments—the person must be actively engaged, and their involvement must be more than tokenistic. For participation to be meaningful, the person's role and contribution must be valued by all those involved in the activity, including the person themselves. (p. 9)

In other words, Moore (2012) is expressing that meaningful participation is the "engine of development and key to attaining a true sense of belonging and a satisfactory quality of life" (p. 9). Engaging in meaningful participation is similar to thinking by King et al. (2003). These authors suggest that people attain meaning (which creates the perception of quality) through *doing* (engaging in meaningful activities), through *belonging* (developing and maintaining relationships), and through *developing self-understanding* (establishing beliefs and values that guide living).

Quality of life concerns. With that discussion in mind, in the research survey, I ask participants, "In your opinion, what are the most important quality of life issues facing your son/daughter today? (You may indicate more than one response)." The fifteen respondents provided 86 quality of life concerns for their children with disabilities (see Figure 8).

None of the participants indicated that they did not have a concern. Rather, the



Figure 8. Theme: Quality of life concerns.

In Figure 8, participants have expressed their fears—quality of life concerns for their children with disabilities. Their child's ability to socialize and communicate with peers and adults concerned most participants. These results are not unlike the literature, providing validity to the results of this investigation. Palmer, Heyne, Montie, Abery, Gaylord (2011), for example, described issues that are occurring with children with

disabilities in the schools. They reported a higher incidence of bullying and harassment for children with disabilities. Moreover, these children have few friends, and there is less participation in extracurricular activities. According to Palmer et al., these children have few connections to others outside the family unit.

Quality of life in the school. To explore quality of life further, I asked whether participants perceive special education as affecting the quality of life for their child in the school. Ten participants (67%) say that they indicate 'strongly agree,' three participants (20%) state 'somewhat agree,' one participant (7%) reports a 'neither agree nor disagree' response, and one participant (7%) says that they 'strongly disagree' (see Figure 9). The majority believe that special education services affect the quality of life for their child or children at school. Responses, however, do not indicate whether special education services are affecting their child or children negatively or positively. Rather, it indicates

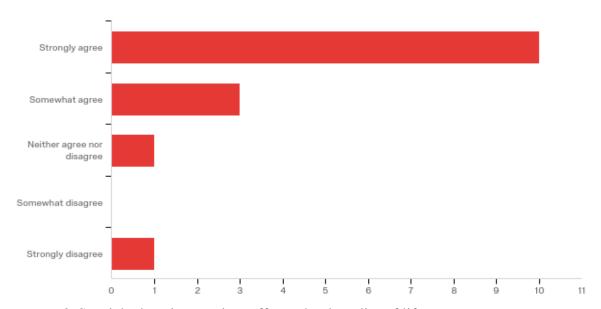


Figure 9. Special education services affect school quality of life.

that special educations services influence their children. As the data shows, one participant believes that special education does not affect their child's quality of life.

Quality of Life at Home. Following the question about school quality of life, i asked how special education affects home quality of life for their child or children with disabilities (Figure 10). For this question, there was a clear shift in responses. Five participants (33%) indicated they 'strongly agree.' Another five participants (33%) reported they 'somewhat agree.' For the remaining participants, three (20%) said they 'neither agree nor disagree,' one (7%) reported they 'somewhat disagree,' and one (7%) identified, again, they 'strongly disagree.' These responses show that participants believe they see progress at school which translates into an improvement in the quality of life, but fewer saw skills that improve quality of life transfer to the home environment.

Quality of life in the community. Following the question about home quality of life, I asked how special education affects community quality of life for their child or children

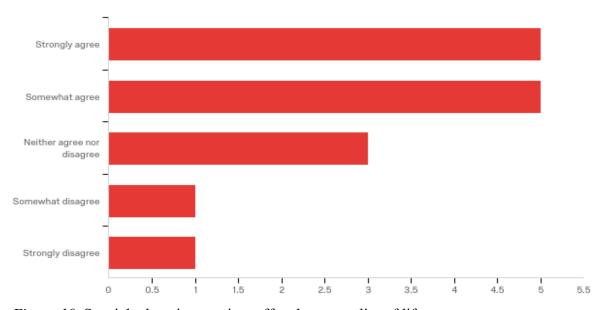


Figure 10. Special education services affect home quality of life.

with disabilities (Figure 11). For this question, participant responses shifted again, indicating participants thought about different aspects of their children with disabilities' lives. Six participants (40%) indicate they 'strongly agree,' with the statement, whereas two participants (13%) indicate they 'somewhat agree,' that special education is affecting their child's life in the community. Five participants (33%) reported that they 'neither agree nor disagree,' one participant (7%) maintained they 'somewhat disagree,' and one participant (7%) said that they 'strongly disagree.' Again, the results are revealing: participants may see *quality of life* improving in the school, but for the community, a third are undecided, and an additional 13% of the participants (2) disagree that special education services improve *quality of life* for their child or children with disabilities in the community.

Quality of life in the state of residence. Following the question about community quality of life, I asked how participants perceive special education affecting quality of life

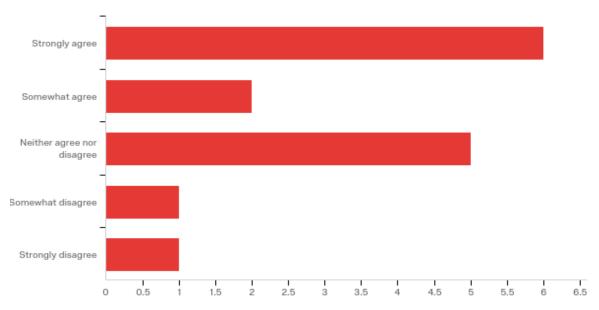


Figure 11. Special education services affect community quality of life.

for their child with disabilities within the *state* they reside, the large community (Figure 12). For this question, the responses shift from those which refer to the child's community, indicating the participants understand the perceptual difference between the child's community versus the larger community. Five participants (33%) indicated that they 'strongly agree,' Two participants (13%) reported, however, to 'somewhat agree.' There were seven participants (47%) who identified that they 'neither agree nor disagree.' And one participant (7%) lists 'somewhat disagree' as their response choice. As most participants selected 'neither agree nor disagree,' the majority were unsure as to whether these services affect their child's quality of life in the larger community. This majority informs me. For them, special education benefits remain opaque.

Quality of life. The last question about quality of life was a general question (Figure 13). It follows four specific questions about the same topic. My goal was to see if quality of life perceptions remained stable. That did not happen; responses shifted again: no participant indicated a 'Disagree' response. Eight participants (53%) state 'strongly

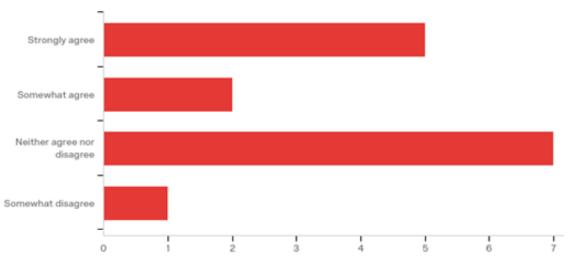


Figure 12. Special education services affect state-of-residence quality of life.

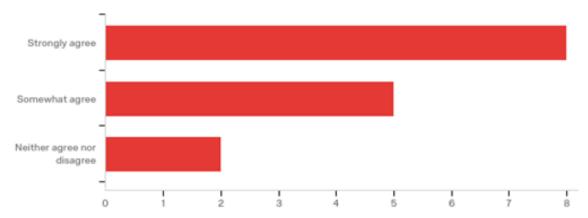


Figure 13. Special education affects your child's quality of life.

agree,' five participants (33%) report 'somewhat agree,' and two participants (13%) indicate they 'neither agree nor disagree.' Perhaps, with five questions about *Quality of Life*, participants began to doubt their initial perceptions or were influenced by the progression toward generality in some way. As a researcher, however, these results inform me about perception survey research and working with small sample sizes. After seeing these results, I surmised that qualitative inquiry needs to support perception survey research to understand a participant's point of view fully and to understand why they responded in the manner that they did.

Quality of life summary. In the above questions, participants expressed their fears—quality of life concerns for their children with disabilities. Most participants are concerned about their child's ability to socialize and to communicate with peers and adults. Most participants believe special education affects *quality of life*. They appeared less concerned with their child's quality of life in the school and more concerned about their child's ability to function at home and in the community. In the following section, participants addressed how they might handle *quality of life* concerns.

Circumventing quality of life concerns. In thinking about the concerns participants express regarding their child or children with disability's quality of life, I

asked each participant what they consider to be an appropriate actionable response to

their concern(s) so that quality of life, in their eyes, could be met (see Figure 14).

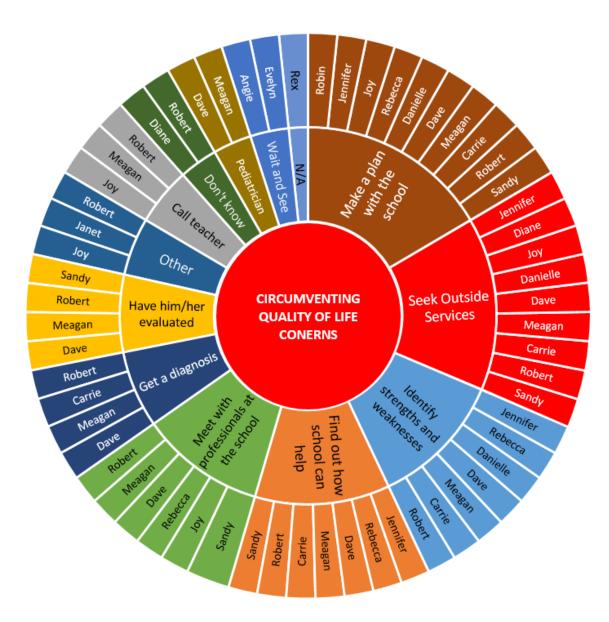


Figure 14. Circumventing quality of life concerns.

Most participants (10, 66%) indicate that they will make a plan with the school. At the same time, however, almost the same number (9, 60% indicate the choice of seeking outside services to overcome *quality of life* concerns. In my view, this response is telling: more than half (60%) appear dissatisfied with the support their child or children are receiving through the school system. It also tells me that while most are willing to make a plan with the school system, they do not believe that their child's school can meet *quality of life* concerns initially discussed.

Fewer participants discussed other actions. Just over half (8, 53.3%) said that they need to identify their child's strengths and weaknesses, Seven participants (46.67%) thought they should find out how the school might be able to help their children improve *quality of life*. Six participants (40%) indicated that they would meet with professionals at their child's school to discuss those concerns, suggesting that around half of the participants view the school as a source of information and planning. A much smaller percentage of the participants (3) reported that they would call the child's teacher, contact their family practitioner or do something else (i.e., other), suggesting participants understood that teachers and doctors might not be able to help them with the kinds of concerns their children with disabilities present. Two participants (13.33%) said that they would 'wait and see,' and one participant (7%) said that a response was 'not applicable.'

In summary, to circumvent *quality of life* concerns, many participants identified that they would plan with the school and even more indicate that they would seek outside services. These participants who said they would look outside of the school for services suggests that they are either not seeing the benefit of specialized instruction or they don't

see sufficient progress and want more for their children than the school is willing or able to provide.

Challenge of obtaining support. I also asked participants about accessing special education within their state (Figure 15). For this question, the majority (9, 60%) perceive a level difficulty for obtaining support for their children with disabilities. The fact that majority experienced problems informs me. Where or how in the process these participants encountered problems remains unclear. That is, participants may be experiencing a problem at entry into special education, or they don't feel support within the services is adequate, or both. Finding out where these nine participants had trouble within that process is important as the special education process concerns me. I address questions of support in the interview Chapters, V and VI.

Challenge of obtaining support, a follow-up. Following the question about state-level Support Access, I asked about accessing special education at the school level (see Figure 16). Through this question, I intended to gauge a participant's perception of their

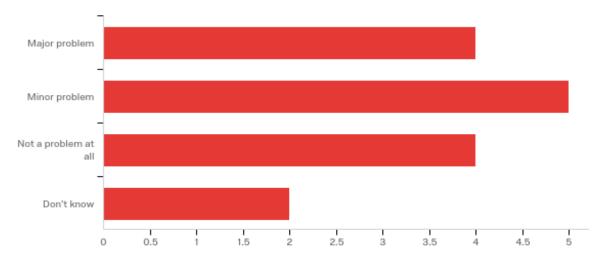


Figure 15. Accessing special education services in your state of residence.

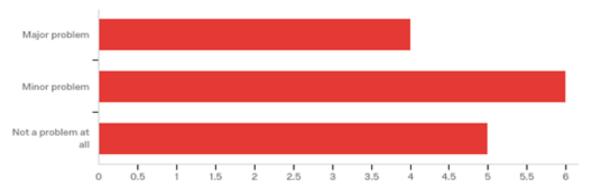


Figure 16. Accessing special education services in at your child's school.

children getting specialized instruction support rather than children in general within their state. In comparing the two questions, there was a slight shift in perceptions regarding the difficulty of obtaining special education support services, 10 participants (66%) versus nine participants (60%) in the previous question. This basic stability of responses suggested that participants used their own child's special education experience to answer the more general question. As stated before, I am concerned with the special education process. As such, discovering where these ten participants had difficulty within that process is of importance. I address questions of support in the interview Chapters, V and VI.

Communicating concerns with a child's teacher. Communicating concerns is both a question of voice and access, a subtheme of equity. If the reader will recall in Chapter II, Literature Review, I discussed the concept voice. I noted that voice is the ability to express a personal point of view. It affords an individual to engage and respond to others, a topic, or a discussion and enables a sense of belonging and well-being. Voice, then, in the context of this dissertation, is having an acknowledged place within the special education process: the ability to be heard. I noted the absence of voice for parents

and their children with disabilities through other research. These works include Garriott et al. (2001); Hauser-Cram et al. (2001); Kaczkowski (2013); Mueller (2009); Salembier and Furney (1997); and Sauer and Kasa (2012).

I also discussed *Equity* and *Access*, tangentially through the work of Kozleski and Smith (2009) who presented the *systematic change framework* (Figure 3) for improving equity in the schools. In that discussion, I referred to the *practitioner* ring and the *school* ring within the model. The *practitioner* ring sits inside the *school* ring. The *school-level* ring affects all that is below it (*practitioner* level and *student* level) but is also affected by *district*, *state*, and *federal* policy (Kozleski & Smith, 2009). I noted that six dimensions define the school level, and all have interplay with *access*. These dimensions include: "(a) governance and leadership, (b) structure and use of time, (c) resource development and allocation, (d) school/community relations, (e) culture of change and improvement, and (f) physical environment and facilities" (Kozleski & Smith, 2009, p. 436). While schools are affected from what occurs above and below, Kozleski and Smith pressed that schools "also influence these other arenas" by how "administrators connect practitioners, reach out to families, use and distribute resources, and structure time, meetings, and agendas" (p. 436).

With that discussion fresh in mind, I was interested in understanding whether perception differences exist between a participant's communication with their child's teacher and the teacher response. For the following questions, participants have 21 categorical, forced-choice responses to consider their perceptions about the way in which teachers interact with them. As teacher support is, in general, an outcome parents with

school-age children desire, I expect high levels of positive responses participants. For instance, Lesley (2004) argues that teachers strive to work together with their colleagues, students, and parents; they do this to make a difference. Stephens (2010) argues that a core mission of early-childhood professionals is to establish authentic relationships between parent and teacher. That is, a goal of early-childhood teachers is to create a bond with the families they serve. They create outreach strategies that support families. These strategies include warm-up visits, home visits, orientations, parent newsletters, workshops specific to parent needs, and hosting support groups, social gatherings, parent-teacher conferences, and family field trips (Stephens, 2010). Moreover, parents sit on educational boards, and they actively engage in their child's evaluation (Stephens, 2010). As such, I anticipate a large percentage of positive responses.

Concerns and teacher. For the survey question, "What do you think of when you brought up concerns about your child to your child's teacher?" responses were mixed (Figure 17). Some participants found communication with their child's teacher productive and easy. For example, Angie during the interview said regarding the teacher, "He was very good about communicating with us. He spent a lot of time with us. He said, 'I am really glad to hear all this;' 'It is really helpful to know more about Thomas, how he functions, how he thinks'" (Angie, personal communication, May 8, 2017). Others, however, reported that communication with their child's teacher was unproductive, confusing, a waste of time, and that felt uninformed following the communication (e.g., "We've asked to observe XXX, the SLP there. And she said yes, but she's never gotten back to us" (Rex, personal communication June 24, 2017).

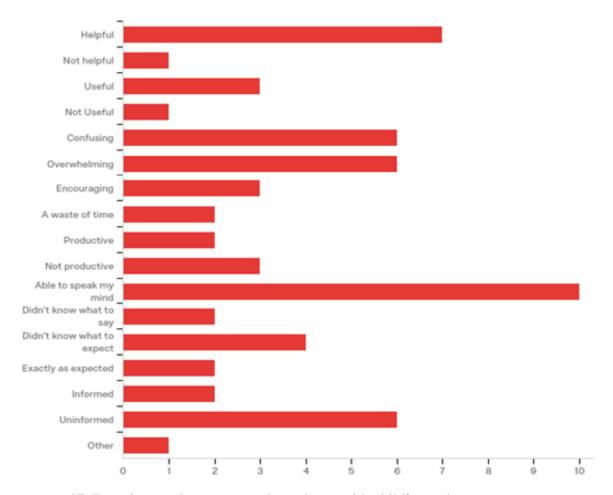


Figure 17. Experience when concerns brought up with child's teacher.

Sixty-one responses are available for review. Ten participants (67%) report that they could speak their mind and two participants (20%) did not know what to say; likewise, seven participants (47%) report helpful communication with their child's teacher, while one participant (7%) reports communication that was not helpful. Only three participants (20%) thought the interaction was useful and encouraging, while one participant (7%) reports the interaction as 'not useful.' Surprisingly, 40% of the participants (6) said that the exchanges were confusing, overwhelming, and they felt uninformed by the exchange. From these data, I conclude teachers, themselves, may not

be well informed about special education process, such as referral procedures, to be able to communicate this information adequately to parents. Within the responses, two participants (13%) stated that the interaction was 'a waste of time.' Only 13% (2) thought that the communication with the child's teacher about their concerns was 'productive.' Twenty percent of the participants (3) reported it was 'not productive.' Four participants (27%) stated the exchange went as expected, while two participants (13%) did not know what to expect. Only two participants (13%) report being 'informed.' Interestingly, in this data, my participants perceive the ability to freely communicate with the child's teacher, but, at the same time, there is a lack of informativeness. Moreover, one more participant indicated the communication was not productive than those who found it productive. Next, participants reported their perceptions about obtaining support.

Regarding *equity/access* and *voice*, most participants reported feeling like they could speak their mind, but just over a third (6, 40%) found the communication helpful and the same percentage were uninformed. Moreover, very few (2, 13%) saw the communication as productive, indicating either they still had unanswered *Equity/Access* concerns, or they were unable to Voice their concerns adequately.

As noted above, I want to see if a difference exists between participants' thoughts about the child-concern interaction with the teacher and the teacher's response to their concerns. To examine this issue, I asked participants not only "What do you think of when you brought up concerns about your child to your child's teacher?" but also "What do you think of when you think about the way your child's teacher responded to your concerns?" (Figure 18). For this follow-up question, I reviewed 56 available responses.

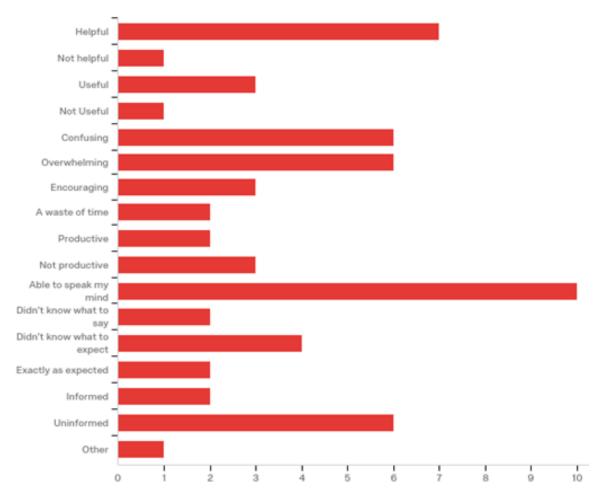


Figure 18. Experience when teacher responded to your concerns.

Seven participants (47%) stated that they thought the interaction was 'helpful.' Ten participants (67%) thought that they could 'speak' their 'mind.' There were two participants (13%) who thought it was a 'waste of time' as well as 'didn't know what to say.' And three participants (20%) reported the interaction as 'not productive,' indicating some stability in the participant's perception responses. In other words, participants may be thinking about the outcome (teacher responses) when responding to the initial question written to examine the initiation of a concern. Interestingly, there was an increase of one

participant to the response "not helpful," 13% (2), indicating at least one person considered the initiation-oriented aspect of the first question and the results-oriented aspect of the second. Participant responses to the distinctive categorical choices 'useful'/ 'not useful' also increased to 33% (5) and 13% (2), respectively. Participant responses for 'Confusing' and 'overwhelming' decreased by half, from 6 to 3 (40% to 20%) while one participant identified the teacher's response as 'clear' (7%). For 'overwhelming,' responses decreased by half from 40% (6) to 20% (3). Also, interestingly, the response 'encouraging' doubled from 20% (3) to 40% (6), indicating that 40% of the participants were at least encouraged by the interaction with their child's teacher. In the responses, one participant thought that the teacher's response was 'fruitful' (7%); whereas, in the first question, no participant thought that the teacher interaction was 'fruitful' (0%). When thinking about the way a teacher responds to parental concerns versus the overall interaction, two additional participants believed the interaction was 'productive' (13% [2]to 27% [4]). There was a decrease in the 'Didn't know what to expect' category. These responses shifted by 20%, from four participants to one. The response 'exactly as expected' increased by one participant, from two participants to three. Criticism about being uninformed also decreases sharply, from 40% (6) to 7% (1); in my view, this indicates that teachers knew about the child and could speak to the issues being raised by parents. The data presented in Figure 16, is not unlike what I have seen as a professional working in the school system. Communicating with teachers (having a voice) is desired and necessary. Moreover, most teachers are receptive to communicating with families; successful interactions typically create successful parent-teacher partnerships and an

environment for learning. While I am not surprised that nearly half of the participants found the communication helpful, it is surprising that 40% were uninformed, confused, and overwhelmed. It is possible that teachers did not have an answer to participant questions or concerns; as such, they felt uninformed. It is also possible that participants were confused by the procedure (what to do next) or teachers did not adequately address the concerns raised. Additionally, it is also possible that participants, not getting an answer, felt overwhelmed with what they should do next in the process.

Special education team interaction perceptions. The next set of survey questions concern interactions within the special education evaluation review meeting and initial IEP meeting. As in the question set, participants have 21 categorical forced-choice responses with which to consider their perceptions about the special education meeting and the way in which individuals interacted with them.

SPED review meeting. Special Education evaluation review meetings are purportedly designed to answer parent questions, identify a child's strengths and weaknesses while utilizing parent input, establish a profile of the child's capabilities, and be a platform for determining whether special education services are appropriate or not appropriate (Bateman & Bateman, 2014). This first question in the set refers to how special education staff addressed participant concerns. Forty-nine responses to this question are available for review (Figure 17). After examination, I found these responses discouraging. As I indicate in my positionality, I am a speech-language pathologist with administrative credentials and have served for 17 years in the schools. I am there to help and serve parents and their children with disabilities. As an example of this

discouragement, while 27% (4) of the participants identified the meeting as 'helpful' and 'encouraging,' an equal number stated they found the meeting to be 'not helpful.'

Likewise, 20% (3) report the meeting to be useful, but an equal number found the meeting to be *not useful* and *overwhelming*. Similarly, only 13% (2) indicate that they found the meeting to be *productive*, while 33% (5) reported the opposite, *unproductive*. Another discouraging finding is that only 5 participants (33%) report being able to speak their mind as opposed to the 10 participants (67%) who reported being able to speak their mind when communicating with the child's teacher. An additional participant (1, 7%) reports that they 'didn't know what to say' during this meeting, indicating a *lack of Voice*. There are four participants (27%) who didn't know what to expect regarding the meeting, indicating a *lack of preparation communication*, while three participants (20%) indicate that they were 'informed' by participating in this meeting.

As stated, most of the data in Figure 19 is discouraging. As I am here to help parents and their children with disabilities, these results should inform practice. I see an equal number who felt helped and not helped. What is being done wrong half the time and right the other half? Moreover, an equal number found the meeting useful and not useful. Is cooperation and collaboration between all parties possible through a meeting that is useful to all parents? When it is not useful, is it because the team lacks the third 'C'—communication? In line with the theme, communication, more participants found the interaction confusing than clear; likewise, more found it unproductive than productive. What practices need to change? Is it educational jargon, the procedure, the policies, or the laws? What are the benefits that parents see? What makes it

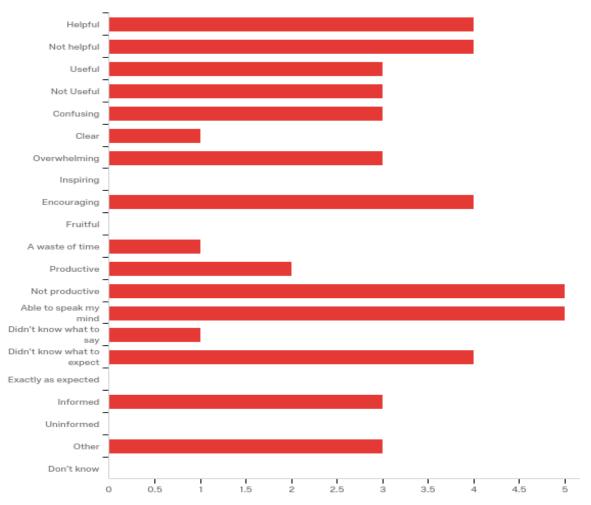


Figure 19. Experience when special education staff addressed concerns.

unproductive? Importantly, why is communication with the teacher more productive than with special education staff? A higher proportion of participants reported that special education team communication was 'not productive' than with teacher communication (previous question set). This data brings forth many unanswered questions, and qualitative case study analysis is necessary to be better informed.

Special education evaluation. In a follow-up question (Figure 20), I ask about the

special education evaluation⁴. For this survey question, I collected 69 responses. Eleven participants (73%) reported that the special education evaluation was helpful. An additional four participants (27%) indicated the opposite; they saw the evaluation as 'not helpful.' Four participants (27%) also indicated that they 'didn't know what to expect,' and the same number indicated that they were 'informed' by the evaluation process. Seven participants (47%) found special education evaluations 'useful' and two participants (13%) stated the opposite; it was 'not useful.' Similarly, six participants (40%) perceived the special education evaluation as 'productive,' and three participants (20%) reported the evaluation to be the opposite, 'not productive.' There are five participants (33%) who stated the special education evaluation was 'confusing' and 'overwhelming.' Three participants (20%) reported it to be 'encouraging' and two participants (13%) said it was 'fruitful.' Twenty percent of the participants (3) reported the special education evaluation is 'a waste of time.' There is one instance of a participant (7%) who 'didn't know what to say;' there was one instance of a participant (7%) who was 'uninformed;' and one instance of a participant (7%) who reported the evaluation process went exactly as expected.

Concerning the data in Figure 18 and reported above, I am more encouraged about these results than the previous question as eleven found it helpful. But why not the other four? Is it that these four participants did not receive the answer they sought? Were evaluation results not adequately explained? Or, did the participants not see the benefit of

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⁴ I kept 'able to speak my mind' and 'didn't know what to say' as special education evaluations that take place through early intervention must and should include parent input and participation. Thorough schoolage evaluations should also include parent input as well.

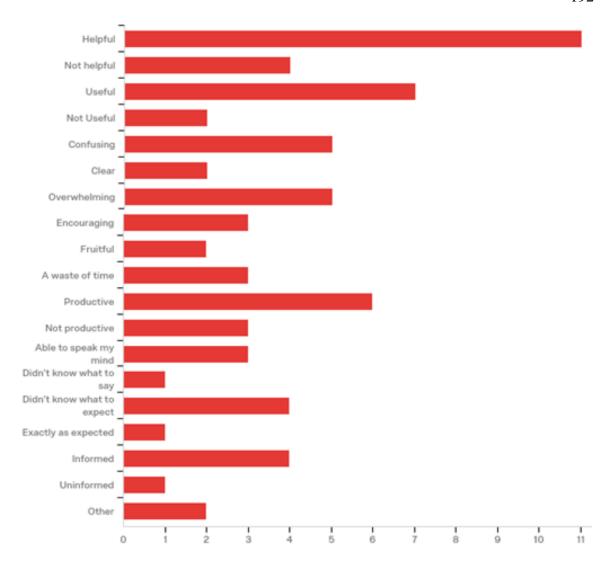


Figure 20. Experiences regarding special education evaluations.

a team trying to understand the strengths and weakness so they could provide help?

Again, only case study analysis can explain this data. In Chapters V and VI, participants attend to issues surrounding the evaluation review.

SPED meeting communication. This research project concerns communication between parents and special education staff within the context of the special education process. To inform that purpose, I asked participants about that communication (Figure

21). I collected 62 responses. Most participants (9, 60%) indicated that they could speak their mind during this meeting. Seven participants (40%) reported that the communication was 'helpful' and 'useful,' while two participants (13%) stated the commutation was 'not helpful.' Six participants (40%) indicated feeling overwhelmed by the way special education staff talked to them. Five participants (33%) reported 'productive' communication and five participants (33%) were 'informed.' Four participants (27%) reported that communication was 'encouraging' and 'not confusing;' three participants (20%), however, indicate that the communication was 'confusing.' Two participants (13%) noted the communication was 'not helpful' and that they 'didn't know

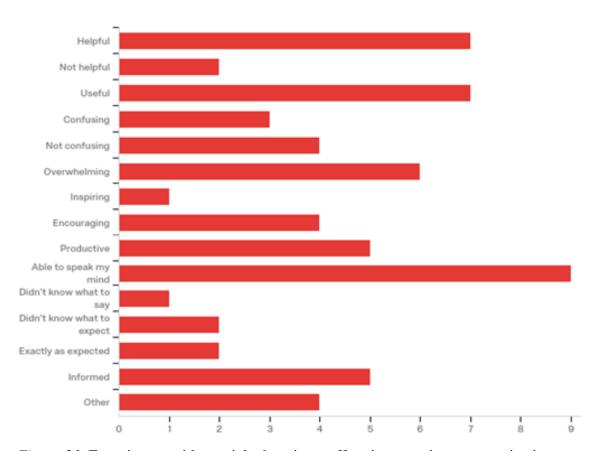


Figure 21. Experiences with special education staff review meeting communication.

what to expect.' Two participants (13%) acknowledged that the communication was exactly as expected and one a participant (7%) felt inspired by the communication and another stated they 'didn't know what to say."

SPED communication about children. Another survey item that relates directly to this project's leading question refers to how special education staff communicate with participants about their son or daughter (Figure 22). For this question, participants can select more than one response. I collected 52 responses. Six participants (40%) and five participants (33%) felt that the communication was 'useful' and 'productive,' respectively. Forty percent (6) stated that the communication was 'helpful,' and 33% (5)

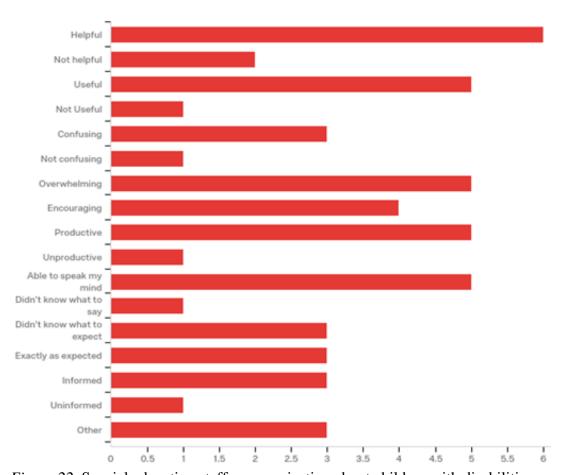


Figure 22. Special education staff communication about children with disabilities.

indicated that they could 'speak their mind.' Twenty-seven percent of the participants (4) in this research project think they experienced encouraging communication while 20% (3) said they were 'informed' through the communication about their children. There were five participants (33%) who found the communication about their child 'overwhelming.' Three participants (20%) perceived the communication about their child as 'confusing.' Two participants (13%) reported the communication was 'not helpful,' and one participant listed the terms, 'not useful,' 'not productive,' and 'uninformed' as the communication that occurred about their child.

Data in Figure 23 are mixed. That is some participants found the communication welcoming, while others felt the opposite, or somewhere in between. If the reader will recall, in Chapter II, Table 6, I discussed MacLeod et al. (2017). These researchers found that parents had concerns about collaborating with educators. Their concerns, according to MacLeod et al., included fear and anxiety due to lack of communication, trust, and negative perceptions about their children with disabilities. When MacLeod et al.'s participants encountered a strengths-based lens regarding their children (among other approaches), their participants were more receptive to collaboration.

IEP as a separate meeting. The following sections apply to only five participants. These five participants had their evaluation review meeting, and the IEP meeting held on separate occasions, rather than at the same time (back to back)⁵. As such,

⁵ Occasionally, evaluation review meetings and IEP meetings are held separately. This is usually done when scheduling is an issue for a parent. ESSA states that the meetings can be held separately, if necessary. Most special education teams prefer to complete the review meting and IEP meeting together, as it allows a child with an identified disability the ability to access services without delay.

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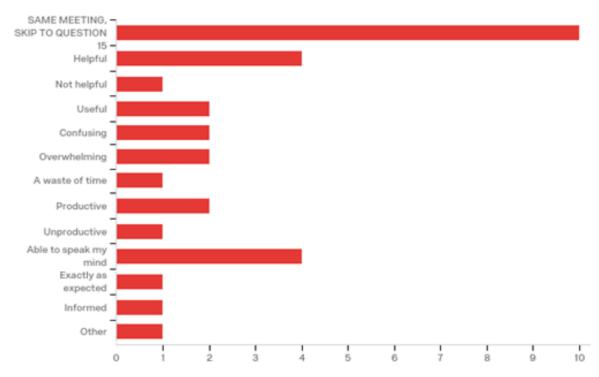


Figure 23. Q11. Experiences with initial IEP meeting.

I report the survey results to three questions from these five participants in the following three sections below.

General perceptions of the IEP meeting. To a question about general perceptions of the IEP meeting (Figure 21), these five participants provided 32 responses. Of the five participants, four indicated that the IEP meeting was 'helpful; one participant, however, reports it was 'not helpful.' Additionally, two participants state that the meeting was 'useful' and 'productive;' there are no reports of it not being useful. On the other hand, two participants report 'confusing' and 'overwhelming' as their perceptions, while no participants say that the IEP meeting was 'not confusing,' 'inspiring,' 'encouraging,' or 'fruitful.' One participant feels that the IEP meeting was 'unproductive,' and one states it was 'a waste of time.' Four of these five participants say that they could speak their mind.

One participant reports being 'informed' and one reports that the meeting 'occurred as expected.' I am encouraged to see most found it helpful and could speak their mind; I am still concerned that one participant reports that the meeting was unhelpful, unproductive, and a waste of time. The fact that two found it confusing indicates that *communication* is still a clear factor of concern, even outside of the special education review meeting where educational jargon as indicated by Childre and Chambers (2005) and Spann et al. (2003) is widespread, burdening, and alienating to parents.

IEP Communication toward Parents. As previously noted, only five participants responded to a question about communication toward parents within the IEP-only meeting (see note 5; Figure 24). As in the questions about the evaluation review meeting that concerned communication, this question, too, informs the focus of this research project. I see this question, though, as supplemental data. The participants had already addressed questions concerning communication when discussing the evaluation review meeting. I asked, 'What do you think of when you think about the way Special Education staff talked to you at the IEP meeting?' The five participants provided a total of 25 responses. Four participants, again, reported that the way staff communicated with them was 'helpful;' No participant reported that the communication was 'not helpful.' Two participants stated it was 'useful;' none reported that the communication was 'not useful.' One participant reported the 'confusing' communication, but none report that it was 'not confusing.' Also for this question, two participants said the IEP communication toward them was 'overwhelming,' while one was 'inspired,' and one reported being 'encouraged.' None reported it as 'fruitful, 'but one considered the communication

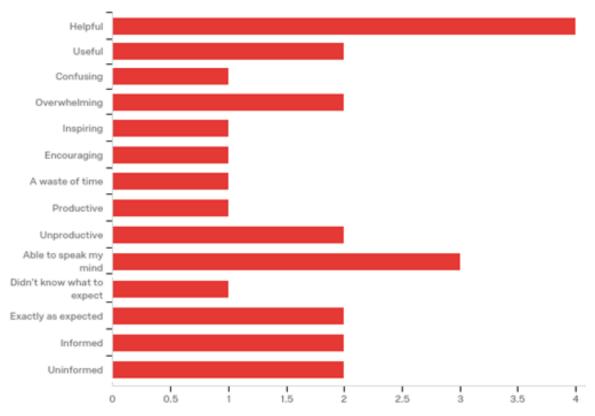


Figure 24. Experiences with initial IEP team meeting communication.

toward them 'a waste of time.' One participant reported that the communication was 'productive;' while two of the five participants, however, indicated that the communication was 'unproductive.' Three noted that they could speak their mind, and none reported that they didn't know what to say. One participant, however, stated that they 'didn't know what to expect,' while another two participants indicated that the communication toward them 'occurred exactly as expected.' Two participants also indicated feeling 'informed' through the communication toward them, and an equal number of participants report the opposite, 'uninformed.'

The results to this question are reflective of the previous question for these five participants. The same number found the meeting helpful, and almost the same number

could speak their mind, four versus three, respectively.

IEP meeting communication about children. As previously noted, only five participants responded to a question about communication toward their children within the IEP-only meeting (see note 5; Figure 25). As mentioned, in the questions about the evaluation review meeting that concerned communication, this question, too, informs the focus of this research project. However, as I stated previously, I see this question as supplemental data as the participants had already answered questions about concerning communication toward their children. I asked, 'What do you think of when you think

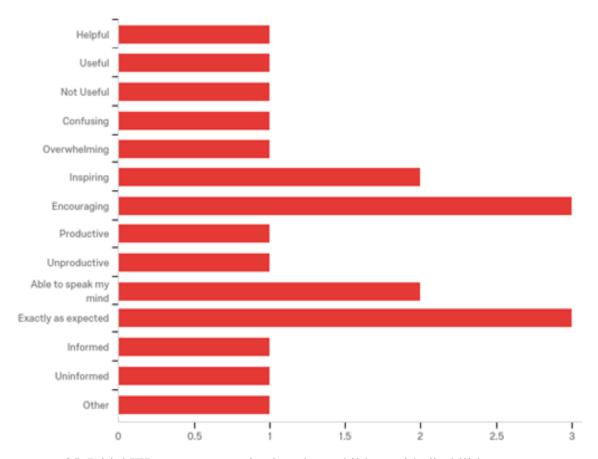


Figure 25. Initial IEP team communication about children with disabilities.

about the way special education staff talked about your son/daughter at the IEP meeting?" This survey question received the fewest responses from those that are similar, a total of 20 responses from the five participants who answered the question, likely indicating question fatigue. One of five participants reports that the way staff talked about their child was 'helpful.' None report it was 'not helpful.' One participant considers the communication 'useful,' while another says it was 'not useful.' One participant considers the communication about their child 'confusing,' one participant indicates the communication to be 'overwhelming,' two report the communication was 'inspiring, 'and three say the communication directed toward their child was 'encouraging.' One considered the communication about their child 'productive' another participant stated it was 'unproductive.' Two indicated being able to 'speak their mind,' and three think the communication about their child was 'exactly as expected.' One notes being 'informed' by this communication, and yet another participant reports being 'uninformed.' This data demonstrates that communication appears team or individual dependent. There is no clear pattern within Figure 23 regarding communication directed at participants' children. As such, communication directed toward their children with disabilities will be a topic for discussion during the interviews.

Services. All 15 participants responded to an opinion question regarding their child's special education services (Figure 26). I obtained 45 responses. Eight participants (53%) see the services as 'helpful,' while four (27%) do not; likewise, five participants (33%) consider the services to be 'productive' and another 33% (5) consider the services to be unproductive. Six (40%) state the services their children receive are 'useful,' and

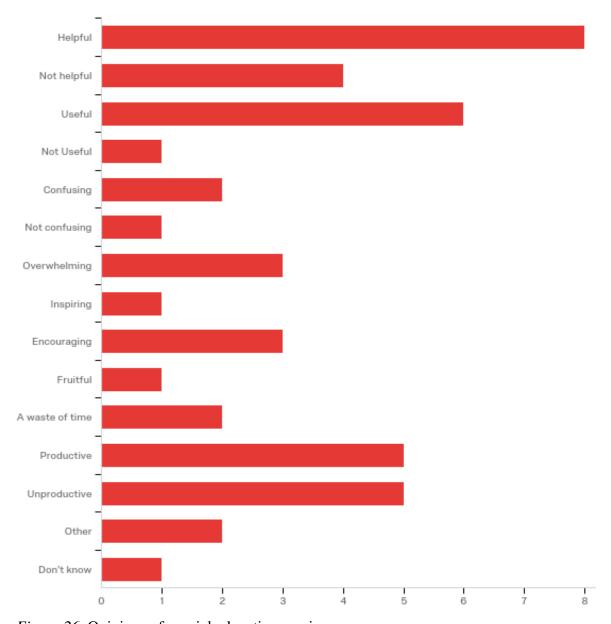


Figure 26. Opinions of special education services.

one participant (7%) reports services are 'not useful.' Two participants (13%) consider the services to be 'confusing' and one participant (7%) indicates services are 'not confusing.' Three participants (20%) are overwhelmed by the services and another three (20%) indicate that services are 'encouraging.' One participant (7%) considers the

services to be 'fruitful,' while 13% (2) consider special education services 'a waste of time.' One participant didn't know about their child's services. One must wonder why no more than eight participants (53%) selected 'helpful.' One would expect that services designed to provide scaffolding to struggling children so that they can access general education curriculum would be 'helpful.' This helpfulness of services data is of concern in light of the fact I recruited participants from five different districts in two separate regions. Based on this data, one could extrapolate and hypothesize that specialized instruction is 'helping' only half of the special education students as seen through the eyes of parents. Participants address this concern in Chapters V and VI.

Attitudes about Special Education

Several survey questions target my participants' attitudes about various aspects of special education. For example, when I engage in dialogue with parents, many bring up issues such as 'labels,' referential devices that can be 'helpful' or 'unhelpful' dependent upon one's ideology (Lauchlan & Boyle, 2007). That is parents do not want their child having a label such as 'autism,' 'cognitively impaired,' or 'emotionally disturbed,' as, many parents believe, these labels have a high degree of negative connotation. They consider these 'labels' to be detrimental to the child. Gillman, Hayman, and Swain (2000), however, argued that a label—a diagnosis—leads to services; it provides an avenue to resources. Likewise, Archer and Green (1996) argued that a label can be helpful if it leads to some interventions that are specific. At the same time, however, Archer and Green also noted that special education professionals might push for labels that provide schools with extra funding, lacking consideration for the child's individual

programming needs. My interest, then, is to see if the participants in this study have attitudes about special education that may or may not bias the interview portion of this research project.

Having a child with a disability. A basic question to ask is how participants feel about having a child with a disability (Figure 27). Fourteen participants (93%) indicate that they 'Strongly Agree' with this statement, while one (7%) indicates that they 'Strongly Disagree.' In my view, this indicates that one participant is having difficulty coming to terms with having a child who has special education needs. Knowing this, I now know to be more extra sensitive with this one participant and to look for patterns or differences in this participant's discourse.

Seeing a child with a disability, others. With another attitude question, I asked participants to put themselves in someone else's shoes when thinking about children with disabilities (Figure 28). I asked, "Seeing a child with special needs in my child's school does NOT upset most people." This question is another way of asking about their perceived attitude of others regarding children with disabilities. In other words, participants who are concerned about 'labels' or who are self-conscious of their child or children with disabilities may respond to this question more negatively than those who have no concerns about a label. Six participants (40%) indicate they 'Strongly Agree,'

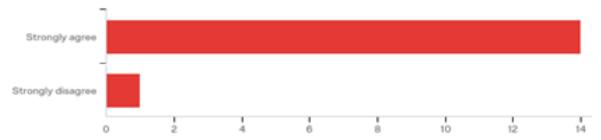


Figure 27. Having a child who needs special education is okay.

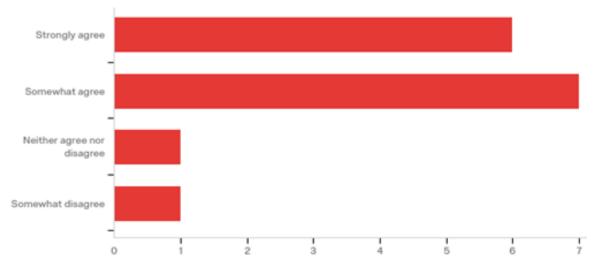


Figure 28. Seeing a child with a disability at school does NOT upset most people.

seven (47%) identify that they 'Somewhat Agree,' one (7%) notes they 'Neither Agree or Disagree,' and one (7%) indicates that they 'Somewhat Disagree.' In my view, this shift indicates that many of these participants are 'somewhat' concerned to 'mostly' concerned about what others think when the topic is a child with a disability. These parents may, for example, be embarrassed by their child's behavior or physical appearance. These parents, by extension, may be more sensitive to discussion of the 'disability' topic. Responses to this question drew a direct relationship to participants' attitudes about labels uncovered in the interviews; this will be discussed thoroughly in Chapter V, Interview Findings.

Seeing a child with a disability, self. After asking participants about 'others' perceptions, I ask participants to consider themselves when thinking about children with disabilities (Figure 29). They responded to the statement, "Seeing a child with special needs in your child's school DOES upset personally." This statement asks participants to reflect on their perceptions of disability. Again, participants who are concerned about 'labels' may respond to this question more negatively than those who have no concerns

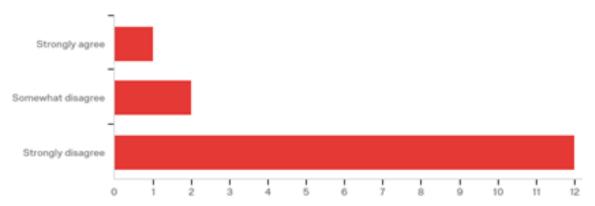


Figure 29. Seeing a child with a disability DOES upset you personally.

about a label. For this research, one participant (7%) indicates they 'strongly agree,' two (13%) state they 'somewhat disagree,' and twelve (80%) report that they 'strongly disagree.' The participants' responses to this survey question indicated that three participants are sensitive to the topic 'children with disabilities,' two being slightly sensitive, and one being sensitive.

Cost of special education, general. I asked participants about their attitude toward the cost of special education (Figure 30). If they believe special education programs cost taxpayers money. Four participants (27%) indicated they 'strongly agree.' Two participants (13%) say they 'somewhat agree.' A third of the participants (5) stated they 'neither agree nor disagree.' One (7%) participant gave the response 'Somewhat Disagree,' while three (20%) indicated they 'strongly disagree.' These results suggested participants are unclear or unsure how their state-funded special education programs.

Cost of special education, district level. For another attitude question, I asked participants a narrower question about cost, whether special education programs are expensive for their school district to operate (Figure 31). This time, four participants

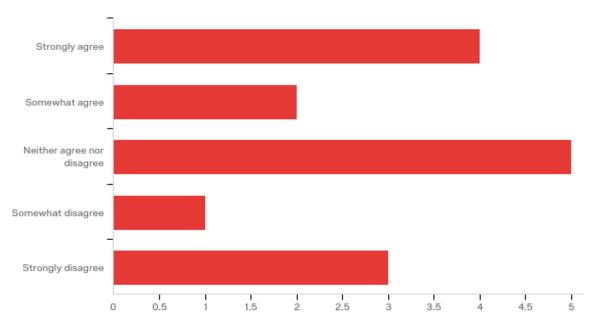


Figure 30. Special education programs cost taxpayers money.

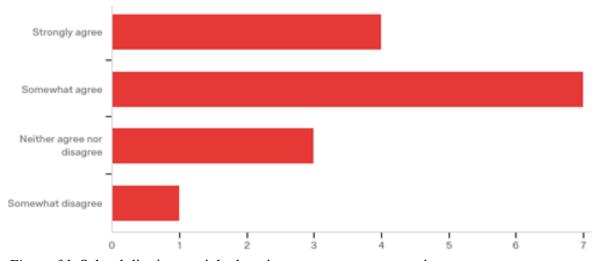


Figure 31. School district special education programs are expensive.

(27%) indicate they 'strongly agree,' seven (47%) report they 'Somewhat Agree,' three (20%) say they 'neither agree nor disagree,' and one participant (7%) identifies that they 'somewhat disagree.' Like in the previous question, these responses indicated that participants remain unclear as to how districts fund special education programs. They

may be considering their background knowledge; that is, what they see at the school to answer the question (e.g., the number of personnel at special education meetings, teacher-per-pupil ratio, student aides, and bussing).

Cost and equity for children with disabilities. As a follow-up to the previous two questions about funding, I asked participants whether special education programs belong in the school system—a question that combines program cost and equity for students with disabilities. All 15 participants (100%) strongly disagreed with the statement 'School districts should spend money on things other than special education programs.' This strong response indicated that while some participants believe special education programs are expensive for districts to operate, all see value and role that special education programs in the schools provide for children with disabilities.

Change. I asked participants a direct attitude question about whether the special education process needs to change (Figure 32). Ten participants (67%) indicated that they 'strongly agree' with this statement. As for the remainder, two participants (13%) stated that they 'somewhat agree,' two more participants (13%) identify they 'neither agree nor

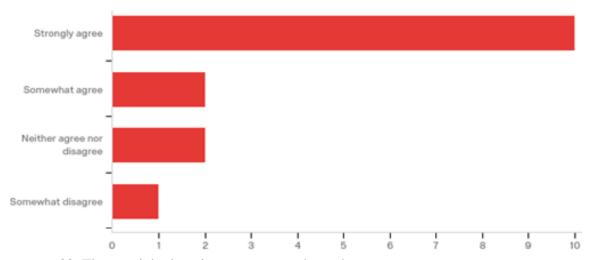


Figure 32. The special education process needs to change.

disagree,' and one participant (7%) reports they 'somewhat disagree.' No participant strongly disagreed with this statement. As this research project is a grounded theory case study, the responses to this question are important and indicate to this researcher that 80% of the participants think that there needs to be some change to the special education process and that this question is worthy of follow-up.

Access to Special Education

I asked two equity survey questions that sought participants' attitudes about access to special education; in other words, do participants believe more or fewer children should receive special education services? I am also interested in understanding whether changing the wording of this question affects the results.

'More' or 'Easier' Access to Special Education. For the first access question, I asked participants if they believed 'more children should be allowed to receive special education services' (Figure 33). As there are eligibility requirements for children to receive access to special education services, another way of thinking about this question is do participants believe that we should loosen federal or state requirements, thereby making it easier for children to obtain special education support and in turn allowing 'more' children into the support system. Within my study, eight participants (53%) indicate that they 'strongly agree' with this statement, one participant (7%) states that they 'somewhat agree,' and six more participants (40%) identify that they 'neither agree nor disagree.' No participants disagree with this statement. As this research project is a grounded theory case study, the responses to this question are important and indicate to this researcher that 60% of the participants think that more children need specialized

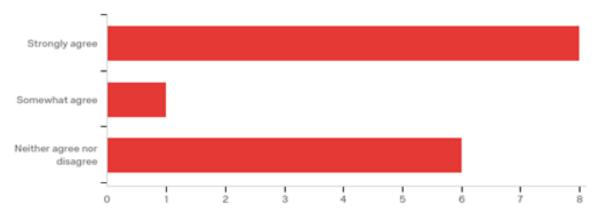


Figure 33. More children should receive special education services.

instruction support or 'easier' access to that support. As such, this question is worthy of follow-up so as fully understand my participants thinking through their explanations.

'Fewer' or 'harder' access to special education. The follow-up access question, targets the same information, only in reverse (Figure 34). This time I ask participants if they believe 'fewer children should be allowed to receive special education services.' As there are eligibility requirements for children to receive access to special education services, another way of thinking about this question is to tighten those requirements, thereby making it more difficult for children to obtain special education support and in turn allowing 'fewer' children into the support system. In the minds of participants, this may, for instance, reduce the financial strain on struggling district. The 15 participants answered this question in the exact opposite of the previous question, indicating stability in their attitude toward access to specialized instruction. Eight participants (53%) indicate that they 'strongly disagree,' one participant (7%) states that they 'somewhat disagree,' and six more (40%) identify that they 'neither agree nor disagree.' There is no participant agreement with this statement. As this research project is a grounded theory case study,

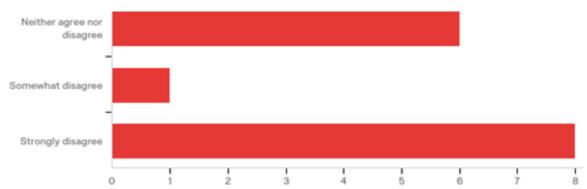


Figure 34. Fewer children should receive special education services.

the responses to this question are important and indicate to this researcher that 60% of the participants think that making special education eligibility requirements more restrictive would be inappropriate for children requiring extra support. These responses are worthy of follow-up with the participants to fully understand their thinking through an explanation.

Attitudes about Power and Voice

Considering the discussion about Power through the lens of Foucault's work in Chapter 1, Introduction, I asked participants five questions directly connected to the investigational questions. As a reminder to the reader, Foucault (2003) views power as three potentially distinct concepts: first, it can serve as a repressive force; second, it can serve as a social relation; and third, power can serve as a productive force. Also as a reminder to readers, the main investigational question of this research revolves around discourses. Specifically, do the discourses parents experience during the special education process function as a tool to empower or disempower? Whom do these discourses privilege? Last, do these discourses function to alienate and marginalize or

unite and value? And is there an alternative explanation? For Paulo Freire, it is important to strive for "social equality," to develop "the dignity of all marginalized people," and give "voice to the voiceless" (Mažeikienė & Ruškė, 2011). Freire (2010) argues that this is accomplished through "authentic reflection" (p. 81) where people are conscious of relationships within society. Linked to Freire's pedagogy is social constructivism, the process of reconstructing social reality between groups of individuals (Mažeikienė & Ruškė, 2011). Freire emphasized that teachers, parents, students, and administrators are "jointly responsible" (p. 80) for a system in which all learn and grow within the community. To address these Power related issues, I asked participants a series of questions that relate to the concept *Power*. I revisit these concepts in Chapters V, VI, and VII.

Power as repression. For the first of these five *Power* related survey questions, I asked participants if they believed they have the same power as other special education team members during their IEP meetings (Figure 35). Importantly, I defined *Power* for them as 'voice, say, authority.' For this survey statement, five participants (33%) indicated that they 'strongly agree.' Another four participants (27%) stated they 'somewhat agree,' two (13%) noted they 'neither agree nor disagree,' and three participants reported that they 'somewhat disagree.' One participant (7%) revealed that they 'strongly disagree' with the survey statement. These results indicated that four participants (27%) felt that their 'voice, say, or, authority' lacked during these meetings. Another 13% (2) of the participants weren't sure whether their voice, say, or authority lacked or not. The remaining nine participants (60%) indicated they had the same power

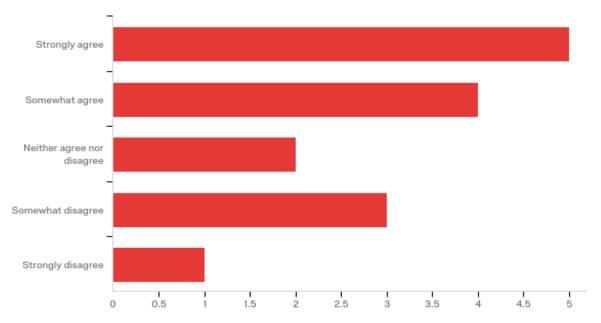


Figure 35. Same power (voice, say, authority) as other team members.

or nearly the same power. Not surprisingly, the participants' responses regarding Repressive Power drew a direct relationship to their discourse during the interviews.

Power as a social relation. To ask about *social relation power*, I asked participants if they felt like a *member* of the special education team who had an *equal* voice (Figure 36). Responses to the previous question about *Repressive Power* and this question about *Social Relationship Power* were stable. That is, except for one participant who shifted their perception of power as a social relation from 'neither agree nor disagree' to 'somewhat agree.' All other survey responses were identical. Five participants (33%) indicated that they 'strongly agree.' Another five (33%) stated that they 'somewhat agree.' One participant (7%) noted that they 'neither agree nor disagree,' three participants reported that they 'somewhat disagree,' and one participant (7%) identified that they 'strongly disagree' with the statement about an equal voice. These

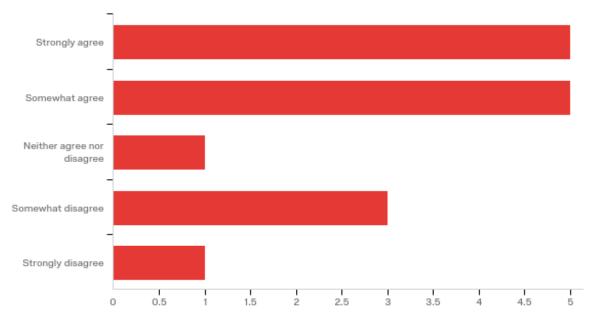


Figure 36. A team member with an equal voice.

results suggest that four participants (27%) perceive the feeling of being a true team member lacked in some form during these meetings. Another 7% (1) of the participants isn't sure whether they felt like a team member or not. The remaining ten participants (67%) report they felt like a team member with an equal voice.

Power as Productive Construct

To briefly remind the reader, Klingner and Harry (2006) note that while the federal law requires the child's parents and teacher to be equal members of the special education team, schools tend to marginalize the perspectives of parents and classroom teachers. Schoorman et al. (2011) support this premise; their study indicates that CST meetings reveal unsettling patterns concerning silencing alternative perspectives and voices. These investigators demonstrated that psychologists tend to dominate the decision-making process and that there are "clear patterns of who was expected to speak

and who was to remain silent" (Schoorman et al., 2011, p. 34). These researchers found that the CST agenda is structured so that school specialists—specifically, school psychologists—do most of the talking, and that time-allotted for parent and teacher input is minimal. In their study, Schoorman et al. (2011) conclude that "there was little expectation that the parent would speak" (p.34) and that "[parents] were there to listen, with little control over how the meeting would unfold" (p. 34). Heatherington et al. (2010) and Spann et al. (2003) argue that meaningful participation from parents continues to be more the exception than the rule, particularly among parents of older students (Harry et al., 1995).

Power as productive, speaking. With the above discussion fresh in mind, I asked participants if they did most of the talking at their son or daughter's special education meeting (Figure 37). Four participants (27%) state that they 'somewhat agree,' one (7%) notes that they 'neither agree nor disagree,' eight (53%) report that they 'somewhat disagree,' and two (13%) say they 'strongly disagree' with this statement. These results suggest that for 10 participants (67%), the other IEP team members or the meeting's

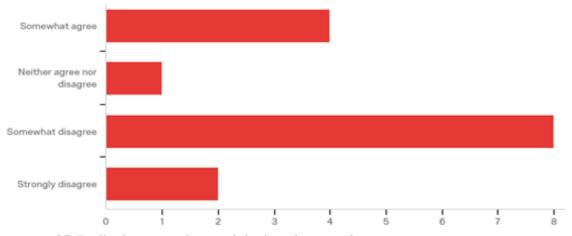


Figure 37. I talked most at the special education meeting.

structure reduced communication opportunities. Twenty-seven percent of my participants perceive that others or the meeting structure do not bind their ability to have *Voice*.

Power as productive, listening. To determine whether the perceptions reported in the previous survey item are stable, I asked participants the reverse form of the statement: "I did most of the listening at my son/daughter's special education meeting." (Figure 38). Two survey participants (13%) indicate that they 'strongly agree,' five (33%) state that they 'somewhat agree,' five more (33%) note that they 'neither agree nor disagree,' and three (20%) report that they 'somewhat disagree.' In comparing these two statements, first, there is no change in the 'strongly agree'/'strongly disagree' dichotomy between 'talking' and 'listening.' Second, there is a seven percent shift in the 'somewhat agree'/'somewhat disagree' response dichotomy between 'talking' and 'listening.' Next, there is a 27% increase in the categorical response 'neither agree nor disagree,' with more participants selecting this response when it came to 'listening.' Following that, there is a 20% change in perception concerning the 'somewhat disagree'/'somewhat agree'

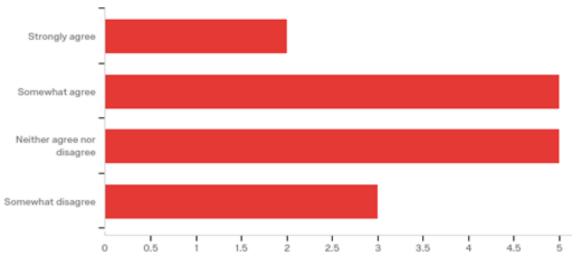


Figure 38. I listened most at the special education meeting.

dichotomy. Last, there was a no change between the 'strongly disagree'/'strongly agree' pairing.

Power as productive. I asked about power relationships through a third question related to speaking and listening to determine if there was any variability or discrepancy in the responses to the power-related survey questions. I asked, "I had an equal voice and did an equal amount of talking and listening during my son/daughter's special education meeting." (Figure 39). For this survey question, four participants (27%) indicate that they 'strongly agree' with this statement. Three participants (20%) state that they 'somewhat agree,' another three (20%) note that they 'neither agree nor disagree,' and four (27%) report that they 'somewhat disagree.' One of the participants (7%) stated that they 'strongly disagreed' with this statement. These participant responses indicate that about half (47%) believe that they had an equal voice and a third (33%) believe that they did not have an equal voice.

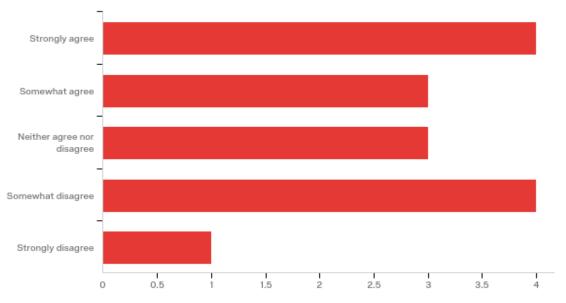


Figure 39. I had an equal voice, talking and listening equally.

In conclusion, I addressed Foucault's (2003) concept of *Power* through categorical responses. This concept or theme informs the reader as to what is occurring within the special education process. As such, it informs the discourses surrounding this process. Participants reflected on and answered questions addressing power as repression, power as a social relation, and power as being productive. While most participants indicated that they felt they had the same voice, say, or authority regarding the special education process, some participants indicate that they felt like they did not have the same power. They felt repressed, their voice unheard, and they did most of the listening. As the reader will see, the responses to these questions draw a direct relationship to participants' discourses during the interview and their comments about feeling unheard.

Chapter Summary

In this chapter, I begin to answer the main research question through survey data. I document through 34 perception-and attitudes-based research questions, the voice of fifteen parents who have children with disabilities. I provide an avenue for their voice through 'forced-choice' categorical response opportunities.

First, participants expressed their fears—quality of life concerns for their children with disabilities. Most of my participants are concerned about their child's ability to socialize and to communicate with peers and adults. Participants were less concerned with their child's quality of life in the school. They were more concerned about their child's ability to function at home and in the community. They also addressed how they might handle those concerns. Many participants stated that they would plan with the

school and even more indicated that they would seek outside services. That a clear majority would seek outside services suggests that they are either not seeing the benefit of specialized instruction or do not see sufficient progress and want more for their children than the school is willing or able to provide.

Next, participants reported their perceptions about obtaining support. In general, participants have a perceived difference in the ability to communicate with their child's teacher and with that of Evaluation Review/IEP team member participants. Two interesting developments from this data are that most participants reported feeling like they could speak their mind in both situations. However, communication with the teacher was more productive than with special education staff; a higher proportion of participants reported that special education team communication was 'not productive.'

Third, participants reported their attitudes about special education issues. Participants responded to questions about having a child with a disability versus seeing a child with a disability. They were also asked to put themselves in someone else's shoes and take on an 'other's' perspective. Responses to this question drew a direct relationship to participants' attitudes about labels uncovered in the interviews; this will be discussed thoroughly in Chapter V, Interview Findings. Attitude questions also addressed the participants' view of the cost of specialized instruction and contrasted it to the equity of children receiving specialized instruction support. The data indicates that while participants are unclear about funding, they are clear that specialized instruction has its place and is of value to children with disabilities who require access to extra support.

Last, the concepts of power were addressed by participants through categorical

responses. Participants responded to questions addressing power as repression, power as a social relation, and power as being productive. While most participants indicated that they felt they had the same voice, say, or authority in an Evaluation Review meeting or IEP meeting, some participants indicate that they felt like they did not have the same power. They felt repressed, their voice unheard, and they did most of the listening. Responses to these questions draw a direct relationship to participants' discussions during the interview and their comments about feeling unheard.

This chapter establishes that there are clear and genuine concerns that parents with disabilities have when engaging in and interacting with the special education process. In the next chapter, Chapter V, I present findings to 14 semistructured interviews that occurred after participants took the surveys. In each case, I drew from the participants' survey responses to assist the interview, but not lead it. I wanted participants to have the opportunity to explain and discuss issues that may have diverged from the literature so that the reader could be informed. The survey, as indicated by several participants, got them thinking about their experiences; they reported feeling more prepared with more organized thoughts at the time of the interview.

CHAPTER V

MAJOR FINDINGS

Overview

Numerous codes emerged from the discourse of my 14 participants. However, six themes resurfaced repeatedly. These themes include Reactions, Power, Advocacy, Dignity, Equity, and Voice. I will discuss these themes in this chapter. Where possible, I utilize literature for discussion. I do this because the themes that emerged directly address the research questions of this investigation. As a reminder to the reader, I seek to understand the following Questions: First, when parents of children with disabilities experience critical moments of the special education process what are the discourses and how do they function to structure the experiences of parents? And secondly, why do the discourses function in the way it does and from those explanations, what is the theoretical model I can build?

Reactions

I used NVivo11 to code *reaction* words used by participants. Using this software, I identified 102 reaction words regarding the special education process. I define reaction words as words that result in a perceptual judgment—a feeling—experienced in response to a situation or an event. Following coding, I conducted a word frequency count and developed two separate word maps to visualize what was occurring in their discourse based on word type and frequency. The font weight increases with the frequency of the word found in the participants' discourses. I present these word maps in Figures 40 and

41. Figure 40 is a Level I figure. It originates from the process of frequency weighting and exact word match (e.g., *sport*). Figure 41 is a Level II figure. It originates from the process of frequency weighting and stemmed words, meaning that the program combines all words with the same stem (e.g., *sport*, *sporting*).



Figure 40. Special education process perceptions: Frequency and exact word match.



Figure 41. Special education process perceptions: Frequency and stemmed words.

The two word-weight and frequency figures above demonstrate a remarkable lack of positively connotated words. For example, the primary visual words are 'frustrating' and 'frustration.' These came from the root word 'frustrate' and have the morpheme stems '-ing,' '-tion,' '-ed,' and '-s' within my study. Participants used this root word with stems twenty-six times as opposed to participants use of 'helpful,' appearing only five

times within the data or 'happy' appearing only four times. In the text below, I present a sampling of the discourse that participants expressed as they reacted to the special education process.

Frustrating. "So, it was a little frustrating, a lot of tears. Sad" (Sandy, personal communication, April 6, 2017). Sandy is describing her frustration with the delay in getting her daughter qualified. She uses the word whole describing the entirety of the process. It took Sandy three attempts to get help for her daughter through school-based specialized instruction. In her discourse, before using 'frustrating,' she also states that it was 'sad' and 'overwhelming,' indicating that the process to get her daughter support was more than she could bear:

The whole thing with my daughter has been kind of sad I guess. You don't want your kid to be delayed and in the beginning, it was overwhelming with all the people there, there was a lot of people there, and they all have their different tests. They had the results from [Place 1] both times. And then, it was the third time that they went through and finally said, "Okay, she qualifies." And they went through each one [assessment] and just from one person to the next and they told me how delayed she was, and the only thing I was thinking was, "I could have been working on it sooner." So, it was a little *frustrating*, a lot of tears. *Sad.* (Sandy, personal communication, April 6, 2017)

Carrie is another participant who uses the word 'whole' as she uses the word 'frustrating' to describe the special education process. She says, "So, the whole process has just been extremely frustrating, and I still am super concerned about what's going to happen when he graduates" (Carrie, personal communication, May 24, 2017).

Carrie is referring to the lack of voices she had during a recent IEP meeting. She paid for her son to be tested outside the district so that she could get answers. Her son was found to have significant working memory issues and a learning disability. The

reaction from the school district was one of dismissal.

We went back to the IEP, I mentioned that, and they were like well, "No. We don't do that here. But we can qualify him under OHI [Other Health Impaired], so we can go with that."

So, I thought I could fight this and go all the way to the state department over it. Or I can just say fine, give him his services. That's all I care about. Whatever the eligibility is, doesn't matter at this point. I just want to make sure he gets support next year.

But it really bothered me that they wouldn't consider anything I had to say. For the last five years, I've been saying Max has trouble in this area, this area, this area, and this area. And they just say oh yeah, yeah, yeah. You're the mom. You don't understand what's going on. We're the experts. We're just going to do what we know is best. (Carrie, personal communication, May 24, 2017)

As a final example, Joy and Rex also refer to the special education process as a source of *frustration*. In their interview, they discuss Sierra's second-grade year where they had five IEP meetings. Sierra is their daughter with an expressive and receptive language disorder. Some of these meetings were about getting the specialized education support staff to not grab Sierra when they wanted behavioral compliance; it was only making matters worse at home and school. Here Rex and Joy recall that event.

Rex: Yeah. So, it took many IEP meetings for us to get our goals in there like we wanted: 'Talk to our daughter. She understands you. She may not react to you. However, she does understand you. You're not allowed to put your hands on her. Do not grab her. That will *frustrate* her.' That was something we wanted in the IEP, and it took us two IEPs to get that in there. And that's something serious for a parent. You don't want your kid. Yeah, you know.

Joy: Yeah, it was completely *frustrating*.

Rex: It was *awful*. (Joy and Rex, personal communication, June 24, 2017)

My participants' discourses align with the NVivo analysis, depicting the special education process as a source of *frustration*. Even when participants used positive words,

they were frequently with a caveat. For example, participants may have used the word 'helpful' or 'happy,' but they qualified it with 'not' (not helpful, not happy) instead of the word choices *unhelpful* or *unhappy*. In the section below, *Dave*, a participant qualifies the word 'helpful.'

Helpful. Dave expresses the word helpful, but it is with a caveat. The special education process to Dave was the problem; the services following, however, were 'helpful.' (Dave, personal communication, May 22, 2017). He and his wife had to formally address the special education staff in letters to get their attention. In the interview, Dave and I are discussing a response to the survey in which he had identified access to special education as a 'major problem.'

Well, in [State A], it depends on how you define that. I was debating, but since I couldn't put somewhere in between a minor problem and a major problem. I put a major problem, because—and I was thinking this across the board. Even for educated parents like ourselves, getting Heather taken care of was a pain in the ass. So, if we, with our backgrounds, had trouble. Maybe not major trouble, but a pain in the hiney, I think it must be a major undertaking for people who are in other situations.... Because of our experience with Heather and then it was a little bit of a pain with April too. Now, once they've realized the kid needs *help*, it was great. But getting to that point was a problem, so that's why I did it that way...

[April and Heather's] teachers were great. April's teacher was even better because she understood the problem. She no longer teaches, unfortunately, but she understood how everything went. She was very *helpful*. For her, I'd probably even go to the point where she was *inspiring* with it. Because she really understood and pushed it.

So, I chose to go with the end result. Because once we got into the process of actually being taken seriously, then it was *helpful*. I didn't go *overwhelming* or *inspiring*, but it was *encouraging*. And that's why I clicked 'other' was because of the desire to click all boxes. And like I said, I also was not involved on the negative side of that much. Meagan wrote the letters. She ran it passed me. I read it to make sure it made sense, but I didn't deal with it too much. (Dave, personal communication, May 22, 2017)

Worried. Four instances of the word 'worried' occurred during participant

recordings. Evelyn's discourse was coded as 'concern' and 'worry about the future' of her son. She didn't know what to expect during her early IEP meetings. And she was uninformed about them. Her discourse reveals how alone she felt. It reveals *self-doubt* and *losing dignity*. The questions she expresses are typically those that should be answered gently and tactfully when 'breaking the news.' When done right, these conversations build trust, rapport, and begin to empower parents with knowledge and understanding. *Evelyn* in this brief text, Evelyn expresses deep *anxiety* about getting her son, Sam who is in eighth grade, on the right track.

Very *stressed*, very *worried*. Because I didn't know what good or bad I was going to do for my child and I wanted him to grow up with, you know, proper speech and pronunciation and I wanted him to have every benefit in life. And I felt when I left most of those meetings that I *didn't have a clue* what I was doing as a parent. And was I going the wrong path or is this the right thing for him? The wrong thing? I was very *confused*, very *worried* almost. (Evelyn, personal communication, April 7, 2017)

Disrespectful. Another perceptual word used by participants was *disrespect*. The use of this word by participants aligns with the literature of Cho and Gannotti (2005), Lo (2008), Park et al. (2001), and Salas (2004), who all reported the theme of disrespect (See Chapter II, Table 2 for that discussion).

Rebecca, the mother of Garrett who is classified as having a Specific Learning Disability and is in the 11th grade, indicated the perception of disrespect occurring within the discourse of the meeting. She stated, "And then, on top of that, it was presented to me in a manner that was *disrespectful*." (Rebecca, personal communication, June 7, 2017). Rebecca is summarizing her perception of an IEP meeting in which she felt voiceless and that the team was just following their agenda.

That shouldn't have happened like that. I felt *talked down* to at the time. And that *didn't make* me *happy* [*unhappy*]. And I felt like it [the IEP] was *incomplete*. But now, I look back and I'm *upset* because it's, it feels like a *violation* almost. Like, I accepted these services that they convince you my child needed that I didn't want in the first place. But I finally agreed, yeah. He probably would do better with them. And then on top of that, it was presented to me in a manner that was *disrespectful*.

Productive and unproductive. Diane, the mother of four children with disabilities, referred to special education services as being both 'productive' and 'not productive' as well as 'helpful' and 'not helpful' (Diane, personal communication, July 6, 2017). Diane is discussing how some teachers follow her child's accommodations and some do not Diane knows that all teachers must comply with a child's accommodations (IDEA, 2007, 34 C.F.R. §300.323(d)(2)). When teachers fail to implement these accommodations, she advocates for her daughter. Diane's concerns parallel the court case *Student with a Disability* v. *SEA Montana* (2011). In this case, there was a failure to implement a student's accommodations as well as failure to inform teachers that a student had an IEP with accommodations to follow (Student with a Disability, 111 LRP 8947, SEA Montana, 2011).

Diane is referring to a question on her survey about teachers where she had checked most of the boxes which included opposites, such as helpful/unhelpful and productive/unproductive. She begins:

So, the *not helpful* is like going to talk to gym guy who didn't give a rip. *Not helpful*: didn't change any of her expectations for her. And like she was in tears about it, not wanting to go to school over it. *Not productive* because he wouldn't let that change and for him, he let me talk, then he was like, "that's crazy." *Condescending*. So, like fine, "I said it." The *overwhelming* is that "I don't know how to help you" [referring to Maddison].

That is probably confusing because sometimes it is *productive*. Like so the English teacher...*super productive* and *helpful*, because I was like, "we have

three of phase one done, and we have two done of phase two, and we have one done of phase three. Can we just call it good?" And the teacher was like, "you bet." So that's what I mean they are *not all awful*, and that might be why it looks confusing.

As I listened to Diane's story about Maddison and the gym teacher, I realized that in all actuality, it was lawsuit worthy if presented factually by Diane, so we talked about it

She was in Gym [in High School]. In middle school, they signed her out of Gym because she has Chiari Malformation, so her brain isn't shaped right, so it restricts the flow of spinal fluid from her brain to her spinal cord. She goes really red when she does physical exercise, and she will get light headed and all that kind of stuff. At the middle school, they just made it, so she didn't have to do gym. She rode her bike; she loves to swim. She does other things and the SLP there just figured it out. We tried to ask for that at the high school. They said heck no. So, she had to do gym.

The *stupid* jock coach. I went and met with him because the tiny things that she was supposed to do an average of so much, she was way, way, way from what everybody else could do.

I spoke with Diane about accommodations for physical activity due to health-related issues. She replied:

So, her accommodations say that she should be able to do less, that we have this other health impairment. That coach, I went and met with him. I asked for him to be at the IEP and he *couldn't be bothered*. I'm sure he was at some sports something or other, but whatever. He wasn't there. I went to meet with him because she has to show so much of an improvement, but she still has some of the loose joints the big sister has. She messed up her ankle three days before the test where she had to improve. She didn't improve. He ended up giving her a decent grade because I had been in her face. But, he was *unbelievable*. He looked me up and down like I am a lug, and I don't do anything. I don't look great, but I can do whatever I need to do. Physically and whatever, you know. He looked me up and down and then he freaked out when he saw her heart monitor that does her pulse. She turned it in, and he saw it and saw how high it was when she was trying to do what he had asked her to do. She was still way behind and not doing as much everybody else was supposed to do. He kinda freaked out so then I think he got a grip, oh this might be a real thing. The thing is that it just takes her forever to recover from, you know, where other kids might have a red face for ten minutes, she's got red face for the next hour and a half to two hours and sweats like crazy.

So, all those things create social [problems] and [it's] not great to go to lunch; plus, it makes her sick, so she wasn't eating. So, then we were missing food and social. But she finished gym. They wouldn't let us not do it. It's not that I'm asking for a cop out, it's that they should follow the accommodations that are set. But they don't. (Diane, personal communication, July 6, 2017)

In Chapter VI, I present summary perceptions and wishes for the special education process. Diane's summary perception is *Effort*, and two of wishes are for more *accountability* and *follow-through*. She wants people such as the "stupid jock coach" (Diane, personal communication, July 6, 2017) to be held *accountable* and *follow-through* on supporting her child; in Maddison's case, it can mean life and death.

Power

A clear and genuine theme that emerged from the participants was their interaction with differentials in *Power* as they maneuvered through the special education process. Specifically, my participants had and shared a perceived *Power Imbalance*. Briefly, in review, *Power Imbalance* refers to one group or individual, typically those in authority or dominant racial class, holding their position as a means of control over an individual or group (Foucault, 2003). Concerning schools and special education programs, those with less power are typically the parent, and by extension, the child with disabilities (Tozer et al., 2009; see Figure 42). This figure shows the theme *Power*, the subthemes, repressive power and productive power, the codes that comprise each theme, and the participants who contributed to each theme.

The theme Power emerged from discourse coded as *Power via Communication* (13 participants, 87 instances), *Power via Procedure* (13 participants, 55 instances), *Power via Lack of Knowledge* (10 participants, 39 instances), *Power via Expertise* (9

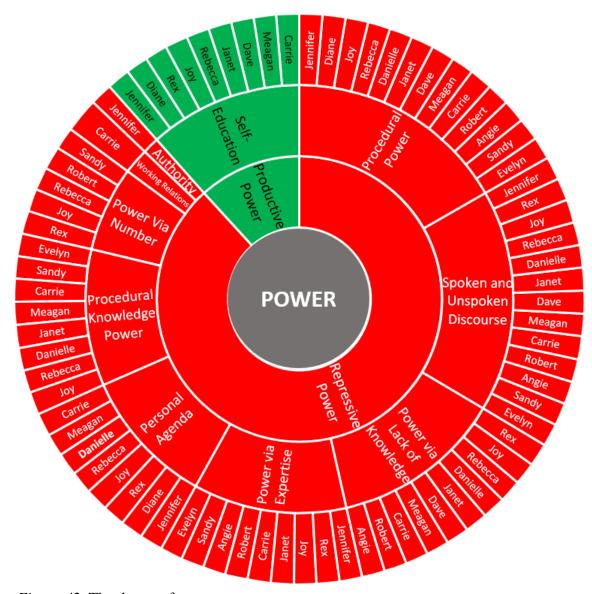


Figure 42. The theme of power.

participants, 26 instances), *Power via Lack of Procedural Knowledge* (8 participants, 22 instances), *Power via Personal Agenda* (8 participants, 53 instances), *Power via Lack of Experience* (6 participants, 9 instances), *Power via Number* (5 participants, 9 instances), *Power via Working Relationships* (1 participant, 2 instances) and *Power Gained through Knowledge* (9 participants, 36 instances).

In Chapter II, Literature Review, I discuss *Power* through the lens of Foucault (2003). In review, he viewed *Power* as *Repression*, a *Social Relation*, and as an object that can be *Productive*. In the above list of different coding for power types, only the last one, *Power Gained through Knowledge*, is considered 'Productive.' The rest result in *Repression*, instances of participants being objects "exclusion, disqualification, exile, rejection, deprivation, refusal, and incomprehension" (Foucault, 2003, p. 44). Or, they result in *Power* as a *Social Relation*, an object used by those in authority for cultural dominance and to impose their viewpoint on the participants (Mouffe, 2000). Because of Power, participants reveal instances of *Dismissal*, *Loss of Dignity* and *Voice*, instances of *Inequity*, including *Humiliation*, *Marginalization*, *Loss of Opportunity*, and *Lack of Academic Progress*.

For nine participants, however, their encounters with *Power as Repression* or as a *Social Relation* resulted in a Productive *Power Gained through Knowledge*. This education led to improved situations for their children with disabilities and ameliorated situations for those who practiced it and led to reported increases in advocacy for themselves and their children. It improved parent and child dignity through recognition and support. *Power Gained through Knowledge* was a tool that allowed my participants to ameliorate the alienation, marginalization, and power inequities they encountered.

So, what does a power differential feel like? Rebecca, the mother of Garrett, a child with an 11th-grade student with specific learning disabilities, answered that question simply: "So, it was very much *me* versus *them* is what it felt like [emphasis added]" (Rebecca, personal communication, June 7, 2017). Rebecca was simply referring to the

room, participants, and seating layout within the room: "I was on one side of the table and the entire profession, there were six professionals on the other side of the table. So, it was very much me versus them is what it felt like" (Rebecca).

I will first present codes that contribute to *Power as Repression* and a *Social Relation*. I will then turn my attention to *Power Gained through Knowledge* and discuss its relationship to *advocacy*, *dignity*, *recognition*, *improved communication*, and *support*.

Communicative power. I uncovered *Communicative Power* in two forms. The first form was explicit discourse spoken to my participants; the second was unspoken communication. Both types of *Communicative Power*, both *Spoken* and *Unspoken*, led to instances of marginalization and inequity for my participants.

Power via spoken discourse. People form perceptions, both negative and positive when those with power or authority speak. For example, Jennifer, the mother of Luke, the 14-year-old boy with a mixed expressive-receptive language disorder, revealed a negative perception within her discourse. In discussing the evaluation review meeting, Jennifer stated, "I just felt like they painted this super bleak picture of where he was at" (Jennifer, personal communication, July 1, 2017). Jennifer's text revealed discourse that is not unlike the literature. She described findings presented from a "culture-deficit perspective" (Klingner & Harry, 2006, p. 2274) or which are "deficit-focused" (Thoma et al., 2001, p. 26). I outlined this thinking in Chapter I, Introduction. It is also not unlike the discourse of the 'medical model of disability' (Grue, 2011) in which the discourse is embedded in "an ideological framework that reduces every aspect of disability to bodily impairment" (Grue, 2011, p. 540). I discussed this argument in Chapter II, Literature

Review. Jennifer's text also parallels the findings of Cho and Gannotti (2005), Park et al. (2001), Ryndak et al. (1996), and Salas (2004), also reported in Chapter II. Last, her discourse is not unlike the pleas for change from MacLeod et al. (2017) whose research reflects the sentiment that "school professionals often reflect a dominant deficit view of disability" (pp. 395-396). Research from Bacon and Causton-Theoharis (2013), Ferguson and Ferguson (2006), Ferri and Conner (2005), Zeitlin and Curcic (2014) support this concept as well. Bacon and Causton-Theoharis (2013), Hodge and Runswick-Cole (2008), and Sauer and Kasa (2012) advocated for a shift from deficit-based views of a child with disabilities to an attribute perspective to achieve family-school collaboration and to support the voice and viewpoint of parents.

Similarly, Rebecca, the mother of Garrett, an 11th grader with specific learning disability, spent a considerable amount of her interview discussing the *Power via Spoken Discourse*. In describing the evaluation review meeting held for her son, she stated, "Simple things were explained to me, definitions that were very commonplace were given to me unnecessarily" (Rebecca, June 7, 2017). In a second instance, *Rebecca* compared special education team members by how they communicated. She stated, "For our process, the teachers were great about communicating, but didn't have a lot of details or information; those who did have details and information, were not great about communicating and were condescending, and not open to change" (Rebecca, June 7, 2017). Rebecca's discourse aligns with McLeod et al. (2017) who found that parents expressed concerns about collaborating with educators, due to fear and anxiety from the lack of communication on the part of the school.

Power via unspoken discourse. Abraham Lincoln said, "Actions speak louder than words" in 1856. In my interviews with participant parents, two indicated sexist actions taken against them by members of the special education process team. In one instance (Joy and Rex), the sexism occurred via a high-ranking administrator, in the second, it was a teacher who had the child with disabilities (Maddison, daughter of Diane) in his class. Swim, Hyers, Cohen, and Ferguson (2001) reported through a series of three investigations that "Everyday sexist incidents have important psychological ramifications, especially for women.... Everyday sexist incidents are a significant source of anger and affect other aspects of women's psychological well-being" (p. 50). Swim et al. also stated that sexist incidents affect a women's comfort, anxiety, depression, and self-esteem. Likewise, Fredrickson and Roberts (1997) reported that gender role beliefs, prejudices, demeaning comments and behaviors, and sexual objectification characterize sexism. They also argued that women may internalize an observer's perspective and objectify their bodies thereby creating the potential to threaten the psychological wellbeing of the women and increase levels of depression.

Joy and Rex discussed interactions with the Director of Special Education who attended their IEP meetings due to on-going difficulties between the parents, the school, and their daughter, Sierra, who has a significant expressive-receptive language disorder. In this interactive exchange, the couple expresses how someone, in a position of ultimate say and authority regarding all special education decisions pertinent to their child, devalued Joy. "So, the director was incredibly sexist towards Joy.

He was such a dick. (Rex, personal communication, June 24, 2017).

It was strange that way. I would present something, and he'd respond to Rex. (Joy)

He was full on sexist. (Rex)

As another example of the *Power of Unspoken Discourse*, *Diane* describes a moment of sexism in which a member of the special education team devalued her.

...he was unbelievable. He looked me up and down like I am a lug, and I don't do anything. I don't look great, but I can do whatever I need to do. Physically and whatever, you know. He looked me up and down. (Diane, personal communication, July 6, 2017)

Another way participants perceived *Power via Unspoken Discourse* was by the absence of *communication*; that is, those in authority were not communicating to parents, marginalizing them, even when the law required communication. The National Center on Response to Intervention (NCRI, 2010) and Fuchs and Oxaal (n.d.) discussed reporting of progress, stating the objective is to inform parents of a child's progress on their goals. The NCRI noted that per IDEA (2007), each goal must have progress monitoring procedures, including frequency of reporting.

Evelyn discussed lack of reporting as did Angie and Joy. For example, when I brought up progress reports, Evelyn said, "It was hard to get updates on how, throughout the quarters, Sam was doing *until* the IEP [emphasis added] (Evelyn, personal communication, April 7, 2017). Likewise, Joy remarked, "I've never gotten an update on anything speech related" (Joy, personal communication, June 24). Joy is made this remark when discussing her daughter Sierra, whose classification and goals all revolve around a receptive and expressive language disorder. Without progress reports, Joy, Evelyn, and Angie are uninformed about their children's progress toward meeting written

goals and objectives that support academic success.

In another instance of *Power via Unspoken Discourse*, Angie, mother of Thomas and Timothy, was speaking about the absence of communication and the frustration and worry it caused. She was speaking about her older son, Thomas, "I never have even met my son's social worker that works with him at the high school. She did not come to the IEP. At the IEP, I said I would like at least a phone call from her" (Angie, personal communication, May 8, 2017).

Angie then summarized the district's policy on what contact meant:

If you are not going to be at the IEP, you have to call the parent ahead of time and talk to them or whatever. You have to try three times before you can say I tried and did not get in touch with them.

The case manager said okay, yeah that is [the social worker]. I will have her call you. Two or three weeks later I still had not heard from her. I emailed the case manager. Hey, can you give me the contact information for the social worker because I have not heard from her?

I do not know whether the case manager told her, and she never got around to it, or whether she never told her. I do not know what happened. Maybe she told her, and she just had not gotten around to it. Again, it was me who kind of led that charge (Angie, personal communication, May 8, 2017).

Angie then revealed why this absence of communication was a concern: Thomas, her son with autism, mental health, and behavioral issues was bullied on the bus, and she was completely unaware.

Thoms had issues on the bus getting bullied. Nobody even ever contacted me to let me know. It was like two months. It had happened in January, and it was March or something. I had no idea that was even happening. She said I am so sorry. I assumed the administration called you. I am like no, nobody called me. Here I find out there is an issue with bullying, which is a big deal, and nobody even let me know. (Angie, personal communication, May 8, 2017).

Angie's concern is justified. Hebron, Oldfield, and Humphrey (2017) reported

that students with autism are at increased risk to be bullied than peers who are developing typically. Likewise, Hebron et al. reported that difficulties with behavior and poor peer relationships increased that risk. These researchers also found that as the number of risk factors increase, the frequency of bullying increases as well. With their teacher model, there was a quadratic effect. The quadratic effect indicated that a disproportionate increase in the likelihood of being bullied exists regarding the number of risk factors reported.

Procedural power. The second largest code under Power was Procedural Power. Procedural Power refers to how those in authority hold the power of mandated and sometimes overinterpreted procedure as a tool for repression. Sandy, Robert, and Janet brought up Power via Procedure when they all discussed the reporting special education evaluations for their children. Robert and Janet had to circumvent this process to get help for their children; both obtained and paid for an Independent Educational Evaluation for their child.

With Sandy, *Power via Procedure* the evaluation review team presented information as they discussed her daughter Chelsea, a girl with multiple disabilities. *Sandy* said with a quiver in her voice and expression of sadness, "And they went through each one [test] and just from one person to the next, and they each told me how delayed she was (Sandy, personal communication" April 6, 2017). During this mandated procedure, *Sandy* experienced the deficit-based framing discussed by Thoma et al. (2001). She also experienced the conclusions of Schoorman et al. (2011) in which psychologists tend to dominate the review process and the "clear patterns of who was

expected to speak and who was to remain silent" (p. 34).

Robert also discusses *Power via Procedure* in his discourse. He first framed how the district used *Power via Procedure*. He then discussed a mandated *Power via Procedure* option available to parents known as an Independent Educational Evaluation (IEE, 2006, 34 C.F.R. 300.502), an evaluation conducted by qualified individuals who are not employees of a school system (IDEA, 2004, 34 C.F.R. 300.503). Sometimes school systems pay for an independent evaluation and sometimes it is paid for by the parent, depending on circumstances (IEE 2006, 34 C.F.R. 300.503(c)). Robert and Angie paid for an IEE, although they could have asked for the district as they disagreed with the formal results. In the end, however, they only cared about getting support for Timothy: "We got teachers [the evaluators] to make a diagnosis once we had a psychiatrist, you know, give him that label" (Robert, personal communication, May 8, 2017).

Janet, the mother of triplets of which two have disabilities—Shawna, who has a Specific Learning Disability and Maci, who has autism—also uses *Power via Procedure* by obtaining an IEE. Janet's discourse, however, also reveals the risk involved in this option. With an IEE, one may provide evaluations for the team to consider during the eligibility process; this evaluation can happen before or after the school system's evaluation. And importantly, although the school system must consider the information provided through the IEE, following recommendations of the IEE is not an obligation of the school. Even though following an IEE recommendation is not an obligation of the school, the U.S. District Court in Maryland ruled that an IEP team's failure to consider the private evaluations submitted by the parents at an IEP meeting was such a serious

violation of the IDEA that it alone constituted a denial of a free appropriate public education (DiBuo v. Bd. Of Educ. of Worcester County, slip no. S-01-1311, Nov. 14, 2001). Janet says:

And we had an evaluation, and the evaluator, the diagnostician, said, 'I'm not, it's not coming up. I think there's something, but I can't find a diagnosis.' And I looked at her, and I said, 'I have nothing against you, personally. You appear to be a sound professional, but I don't know you. And I know my child, and I want to get outside testing, because I know she has dyslexia.' Like, at that point, there was no talking me out of this. And I paid for outside testing, and sure enough, they said, yeah, this child has dyslexia. (Janet, personal communication, May 22, 2017)

Janet has good news in her hands. An Independent Evaluator identified Shawna's difficulties. Shawna had thorough but expensive testing. Janet continued:

Well, at first, I was told, well, because of her last testing, she scored really well. They were not sure if she was going to qualify. It's so; I'm like, are you waiting for her to fail? Are you waiting to get sued? And I said, rest assured, I will not stop. (Janet, personal communication, May 22, 2017)

After this exchange, however, the school district within which Janet resides, chose to support Shawna's needs.

In my next example of Power via Procedure, I discuss Meagan. She is a special case when it comes to Power via Procedure. Megan informed me how she was fortunate to usurp the process concerning her daughter, Heather, getting her daughter qualified before summer break, in three days—including permission, testing, report writing, drafting IEP and eligibility reports, and holding the meeting. Although Meagan did not ask her neighbor to intervene, she believes that her next-door proximity to the superintendent and her friendship with the principal played a clear role. Meagan felt that others, not in her situation, are unable to circumvent the special education process.

Meagan said:

Literally, before all of the official things were done. I mean, I know there's a legal chain of the process, and it was not followed, which I have no problem with. I would never—but for other people, there's no usurping the process. It happened because I live next door to [Superintendent A]. (Meagan, personal communication, May 22, 2017)

In my last example of *Power via Procedure*, I revisit *Carrie* who is discussing the testing her son *Max* experienced. To refresh, *Max* is in eleventh grade and has a significant Specific Learning Disability in the areas of language processing, comprehension, reading, oral, and written expression. *Carrie* is also talking about the Power that Evaluation Review Teams hold over parents who are only seeking support for their children. *Carrie* said, "So, they only agreed to do testing in the areas of language and psych testing for anxiety. Because they said the Diag's assessment was valid and there was nothing I could do to disagree with that. (*Carrie*, personal communication, May 11, 2017). In other words, the district was withholding language testing—the primary area in which *Max* has difficulties—based on cognitive testing. The school's team figured it had done enough by doing the minimum required, missing the problem.

Lacking knowledge, procedural knowledge, experience, and expertise. In the discourse of my participants, four closely related codes emerged, all having to with a power discrepancy specific to information held by team members but not held or shared with my participants. This discrepancy created instances where those in authority dominated participants due to their *Lack of Knowledge*, *Experience*, or *Expertise*. I discuss these codes as they relate to *Lack of Power* here.

Joy and Rex present discourse that reveals frequent referral to Lacking Expertise

concerning their daughter. Their discourse reveals disdain for those who practice this kind of power. While initially they "just went with the flow" (Joy, personal communication, June 24, 2017), the situation changed when staff started physically handling Sierra. In their text, they are referring to the special education director who attended their IEP meetings. This director is a reported "expert" on autism; however, Sierra's diagnosis is not autism, it is mixed expressive-receptive language disorder. The director disagrees with this diagnosis even though he has never personally tested her:

So, the director of our, of XXX County, he is an expert on autism. So, us being the experts on Sierra, we weren't treated as experts on Sierra; we were treated as you know a general contractor and a person with an anthropology degree. You know, so, [chuckle] even though we are the people, who know our daughter the best. Yeah, we had a voice without any real, I guess we weren't accredited in their eyes. (Rex, personal communication, June 24, 2017)

Joy referred to this *Power* more simply, "Total ego" (Joy, personal communication, June 24, 2017). Rex agreed: "It was ego." And then Rex continued: "I think the IEP process could be improved if they just set aside egos, and it was officially all about, I mean not officially, but in essence all about the child. But I don't think it is" (Rex, personal communication, June 24, 2017).

The discourse of Evelyn and Dave reveals *Power through Lacking knowledge* and *Lacking procedural knowledge*. With Evelyn, she reveals *Lacking knowledge* results in a loss of *Power* as we discussed Sam's initial classification and enrollment into special education.

Originally, I had no clue [laugh] so no. There was no interaction. It was them telling me what they were going to do. I knew the speech pathologist was the speech person, and the gifted counselor was the gifted person, but I didn't know what my role was.... I think one of my big still pet peeves at this point with the special education program is that the people in the IEP meeting know what's

going on, and I still don't. (Evelyn, personal communication, 2017)

Dave, on the other hand, talked about Lacking procedural knowledge within the context of professionals within the school when discussing April. This lack of procedural knowledge led to a differential in perceived Power.

I don't think the teacher was aware she could ask for it either. In fact, I don't think she even—I mean, if I understood what Meagan said correctly, but I don't think she was even aware of the fact that she could call in a meeting and request the initial stuff. (Dave, personal communication, May 22, 2017)

Dave is commenting on the referral process to the Student Assistance Team (SAT process). This a standard special education procedure that exists to benefit and track atrisk students. First-year teachers are typically briefed on it during orientations and school faculty experience a review of the process at the beginning of the school year. When an individual refers a student to SAT, the student moves from a TIER I (a general education student) to a TIER II student (monitor, intervene, accommodate, and modify). When students leave the SAT process, they either return to a TIER I status because of improvement or are referred for testing to determine eligibility for special education, TIER III (Gersten, Newman-Gonchar, Haymond, & Dimino, 2017; Stoehr & Isernhagen, 2011).

Danielle, the mother of three children, was discussing her daughter who is gifted when her discourse revealed a differential in *Power* that occurred via a teacher *Lacking experience*.

It's as if there's a disconnect between knowing what is required and what is allowed, especially for the teachers knowing how to facilitate it. I do not know if it was just because of experience because her first-semester teacher was older. Her gifted teacher is older. They have been doing this for a while, so they have more experience. I think this new teacher, I think she just did not even see that

that could be a problem on the horizon. That this would now put this child into fits.

Personal agendas and authority. As I coded the discourse of my participants, I saw a relationship between an individual's *Personal Agenda* and their *Authority*. I also noted in the participants' discourses that the more those in power tried to wield their authority, the less successful they became in negotiating an amicable outcome with my participants. In discussing *Power* and *Motives*, Marshall (1990) stated:

The conundrum of power is that the less power a leader grants to people, the less powerful the leader becomes in the eyes of the people. Individuals have a need for power though they tend to deny the need's existence; acknowledgment of the power motive must precede any mastery of the conundrum making up the powercomplex of leadership. (p. 1)

In other, words, "acknowledgment of the power motive" (Marshall, 1990) means being self-aware and even self-critical of one's motives, ideologies, and beliefs. It is akin to my positionality, discussed in Chapter I. There, I refer to the words of Mohandas (Mahatma) Gandhi. Gandhi purportedly said, "Three quarters of the miseries and misunderstandings in the world would finish if people were to put on the shoes of their adversaries and understood their points of view" (Greenburg, 2015, slide 3 of 8). Through acknowledgment and self-reflection of the power motive, one can begin to understand others. It allows for an ideology that is constructed piece by piece, from authentic, lived experience; one that develops from a place of sincere concern for the well-being of others.

Joy and Rex had a lengthy conversation with me about *Personal Agenda Power* that results in *Power* differentials. If you will recall from above, Joy and Rex spoke about the Special Education Director and his "ego" (Joy and Rex, Personal Communication,

June 24, 2017) when their discourse revealed *Expertise Power*. As they discussed this further, their discourse reveals *Personal Agenda Power* which compounded the *Expertise Power* differential that they experienced with the Director of Special Education whose expertise is purportedly in the field of Autism.

Joy and Rex (personal communication, June 24, 2017) begin their story by talking about preschool, kindergarten, and first grade. In those grades, there were no real problems; however:

It was second grade where we started having to research the testing that they were giving Sierra and having to educate ourselves because they were *pushing their agenda* on us and just trying to get us to jump onboard. (Joy)

Rex replied, "Because the funding was in autism."

Joy responded:

Well, that's what we think. We don't understand but they wanted that diagnosis [Autism], and there was nothing else that they wanted to do but that diagnosis. There was no other option.... They then told us that we would lose support completely if we didn't go along with it. That we would not get, at that point, she had a paraprofessional. And she got accommodations for testing, like all that. That we would lose everything. And that didn't feel right. (Joy, personal communication, June 24, 2017)

Rex then explained their action they took upon hearing this news, "We took her to Vanderbilt? And they diagnosed her as having an expressive and receptive language disorder" (Rex, personal communication, June 24, 2017).

Intrigued, I asked what happened next. Rex's reply was, "They [the Evaluation Review Team] just discredited it" (Rex, personal communication, June 24, 2017).

As noted earlier, under *Procedural Power*, a district has the right to reject an IEE.

Also, as mention earlier, however, the U.S. District Court in Maryland ruled against

failure to consider an IEE. It is a serious violation of IDEA. This refusal to consider an IEE constitutes a denial of FAPE (DiBuo v. Bd. Of Educ. of Worcester County, slip no. S-01-1311, Nov. 14, 2001).

I asked if the team evaluated Sierra for autism or other disability considerations.

Rex replied, "Not officially." Then Rex added, "But his [the Director of Special Education's] unofficial evaluation was that we were wrong. And the SLP was just backing him" (Rex, personal communication, June 24, 2017).

Joy then explained more about how this agenda was marginalizing Sierra.

And we even said at one point, like what would change. Like if we just go with this, what services would be different? I mean it would be different in that we were going to lose services, but they wouldn't suggest any different services whether we went with what they wanted to say the diagnosis was or outside sources.... At the time it was just, we wanted Sierra to be able to have the opportunity to talk. You know what I mean? I feel like if you get a diagnosis, that's your life. (Joy, personal communication, June 24, 2017)

Rex responded to Joy's comment. "They pushed for us to put Sierra to in the special-ed class [Self-contained classroom]. They had their own agenda" (Rex, personal communication, June 24, 2017).

Joy, however, disagreed about the specifics of the personal agenda: "I think it was this specific diagnosis" (Joy, personal communication, June 24, 2017).

Rex acknowledged Joy with agreement:

So, it was. *THAT* was their agenda. In my opinion, they marginalized Sierra, our daughter. And [they] wanted her to be out of the regular classroom and babysat. I believe their agenda was to get rid of the disruption in class and so the regular classroom could proceed as they're supposed to, and Sierra could wither on the vine in the Special Ed room. He was pushing that agenda to get funding and to get Sierra into Special Ed full-time. (Rex, personal communication, June 24, 2017)

Power in numbers. The discourse of Sandy and Robert reveals how *Power in*

numbers creates a perceived *Power* differential. Sandy, the mother of Chelsea, a 9-year-old girl with multiple disabilities, said, "There was a lot of people there, and they all have their different tests. It was overwhelming with all those people there (Sandy, personal communication, April 6, 2017).

Robert, the father of Thomas and Timothy, made a similar statement, "there's so many voices on that side of the desk plus the person who's running the show" (Robert, personal communication, May 8, 2017).

Working relationship power. The discourse of Carrie revealed an interesting type of *Power*. Carrie is both a participant (parent) and an employee of a district. Her discourse revealed *Working Relationship Power*, arguably a type of ethical maltreatment (Melé, 2014). In Carrie's case, the IEP specialist (site specialist)—the person in *Power*—circumvented federal and state law as well as district policy and procedure by taking a shortcut. Carrie stated: "The site specialist at that school, because I work at that school, just said here's her report. Do you have any questions? No, okay great. Let's just do the IEP" (Carrie, personal communication, May 24, 2017). This shortcut marginalized Carrie and her son Max by not providing her Carrie with needed information to support her son at home, pushing the boundaries of FAPE (IDEA, 2007).

Melé (2014) presents an organizational tiered model for thinking about *Power*, ethics, and working relationships (see Figure 43).

In this model, the lowest level of Human Quality Treatment (Level 1) is Maltreatment; it involves injustice through the abuse of Power (Melé, 2014, p. 463). Maltreatment is where Carrie's discourse is situated. The abuse of Power by the site

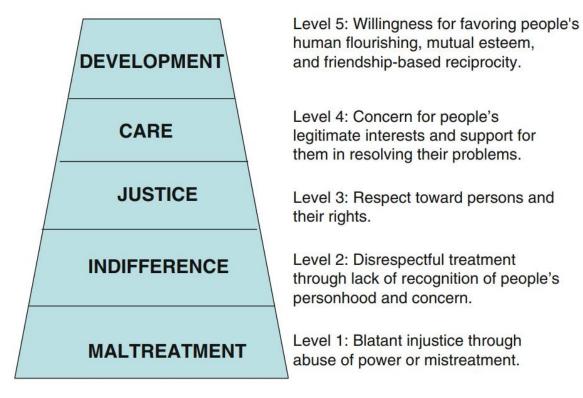


Figure 43. Five organizational levels of human quality treatment (Melé, 2014).

specialist led to marginalization, an injustice. The next level is *Indifference*. Indifference involves disrespect. It occurs through lack of recognition (e.g., parents who 'voice' concerns but are not acknowledged). The following level is *Justice*. At this level, those in power show respect toward others and their rights. *Justice* would be shown, for example, by having an administrator following the law. The fourth level, *Care*, follows. At the level of *Care*, those in power show concern for other's interests and support them however they can. Melé's highest level is *Development*. Leaders who help others grow characterize this level; it is collegial and friendship-based. At this level, growth in self-esteem is a genuine outcome. In Chapter VI, I revisit *Carrie's* story of maltreatment in detail, discussing the impacts of the administrator's actions revealed through her

discourse. I provide this discussion under the heading, *Frustration*.

Knowledge as power (empowerment). The last type of power uncovered in the discourse of my 14 participants was *Knowledge as Power* or *Empowerment* a type of 'Productive' Power (Foucault, 2003). Carrie, Meagan, Dave, Janet, Rebecca, Joy, Rex, Diane, and Jennifer all revealed this type of productive power in their discourse.

Vuorenmaa, Halme, Perälä, Kaunonen, Åstedt-Kurki, P. (2016) discuss *Empowerment* through decision making and access to information regarding parents. Vuorenmaa et al. noted that *Empowerment* connects to internal resources and a perceived sense of ownership regarding one's life. Mendez (2010) reported that empowerment provides a sense of confidence and a platform to exercise that influence tangibly. Koren et al. (1992) measured empowerment through a questionnaire given to families whose children had emotional disabilities. These researchers found that empowerment builds opportunities for decision making and participation allowing individuals to better engage with family, organizations, and society. Gallant, Beaulieu, and Carnevale (2002) and Øien, Fallang, and Østensjø (2010) reported that associated with parental empowerment are self-efficacy, improved resources, and reduced stress. Vuorenmaa et al. also discussed positive associations between parental empowerment and their experiences of service accessibility and adequacy of support.

Rebecca's discourse reveals Knowledge as Power or Empowerment. She discussed occupational therapy and how her son, Garrett, when he first tested needed that service. She did not know that she could request an evaluation. Because occupational therapy cannot be a stand-alone service, the team informed Rebecca that her son could

not receive that service. However, when her son became eligible for gifted education, he could also have been tested for occupational therapy concerns and received any needed services at that time. That testing was not done or even suggested by the school. *Rebecca* said, "I know that now. And at that time, I didn't realize... I mean, as a parent on the outside looking in, even with some understanding, it's very confusing (Rebecca, June 7, 2017).

Rebecca's discourse then reveals how she learned that Garrett could have been benefiting from occupational therapy support:

I didn't even know until this semester. This is my second year working in the school. And I only, I was just talking to an IEP specialist at my school about Garrett, about the situation. And she's like, 'he could have been eligible for OT services at that time.' And I was infuriated. I was angry. Because he could have benefited greatly.

I was so ignorant of what should have happened that it didn't feel like it was all that bad. It was only after I finished Grad School and then got into the schools as an SLP that I was like, 'Now that was unacceptable.' It was totally unacceptable (Rebecca, June 7, 2017).

At this point, I was curious as to how this experience had changed Rebecca. Not being informed and not knowing what to ask or that she even could ask had resulted in a loss of FAPE for her son. As she was now providing services to students, I wanted to know how becoming empowered by this knowledge might have changed the way she practices as a speech-language pathologist. So, I asked, "Since you've sat on the other side of the table and experienced this, what are you doing internally to make the process better for other parents?"

I could tell you a million things that I do. Because it's so important to me that nobody ever is treated like that by me. So, with a child's strengths, I never go into academics first. I'd say, little Danny loves comic books and enjoys writing comic books during Speech Therapy sessions after he's earned X and X, whatever

rewards.

He does not like sitting with girls, and he hates the sound of the tree on the window. So, the parent has an idea of what he looks like at school. Because kids are always different at school than they are at home.

And then I go into academics. I always get beside the parent. That parent is never going to sit alone as long as we're there. But my school already doesn't do the 'us' versus 'them' seating. We're all seated together looking at a screen. But I try to make sure I'm the one sitting right next to the parent. That way, if they need help, or if they need to stop, I watch for that.

I think my school does a really good job of not bulldozing parents. But sometimes you do get caught up in going to the next section, and you don't always see if a parent wants to stop. And especially with my school, if a bilingual parent or a monolingual parent that doesn't speak English is not catching something quickly enough and you go on. Sometimes the person who's running the projector doesn't notice that.

I put 'draft' on every page of the IEP so that they can see that we usually send it home and we write 'draft' in highlighter. And that way, they can change things. I also add sticky notes for the parents to change and add things that they want.

And then when they come into the IEP, and I introduce my goal whether I'm part of the team, or I'm leading the IEP, I say this is what I've tentatively come up with. How do you feel about this and what would you like to change? And I go into that [the meeting] assuming that they will want to change something. And they may not like it, and I'm okay with that. And none of my goals are ever exactly the same. (Rebecca, personal communication, June 7, 2017)

Rebecca, in the text above, is empowered by her experience and knowledge discovery. She has modified her practice as a result. She discusses strengths in a personal-relatable way demonstrating that she knows the child. Rebecca sits beside the parent, making the parent feel welcome and "not alone." She is also sensitive to her body position so that she can catch subtle cues from the parent and is sensitive to bilingual families in which the process takes longer due to language barriers. Furthermore, she writes 'draft' on each page, sends it home for review, provides the parent with cues such as sticky notes, and uses language that expresses the document and goals are up for

discussion. Importantly, Rebecca individualizes her goals to meet a student's specific needs.

Advocacy

A third theme that emerged from the discourse of my 14 participants was Advocacy (see Figure 44). Advocacy is the process of championing support for yourself or others. Typically, the advocacy is for a cause or policy. All 14 participants revealed instances of advocacy for their children with disabilities. Advocacy also emerged on the Part of the School, on the part of the Child with disabilities, and on the part of Outside Agencies. Even though parents, schools, children with disabilities, and agencies all demonstrated instances of advocacy, it was not always successful in achieving the desired outcome. At the same time, the discourse of my 14 participants also revealed instances of a Lack of Advocacy on the Part of a Child with Disabilities, a Lack of Advocacy on the Part of a Parent, and a Lack of Advocacy on the Part of the School.

In Chapter II, Literature Review, I briefly reviewed advocacy literature. I noted that the need for advocacy has arisen from reported power differentials (Leiter & Krauss, 2004) which have led to disempowerment and weakened partnerships between the school and family (Leiter & Krauss). Other literature noted that parents lack legitimacy within the special education process (Kalyanpur et al., 2000) or are disempowered by lack of knowledge about their child's special education rights (Rodriguez et al., 2013).

Importantly, here, I reported recent work by Burke (2017) who had discussed the work of Jones and Prinz (2005). Burke wrote that "when parents have greater empowerment, they respond to challenges with optimism, leading to improved child outcomes" (p. 57).

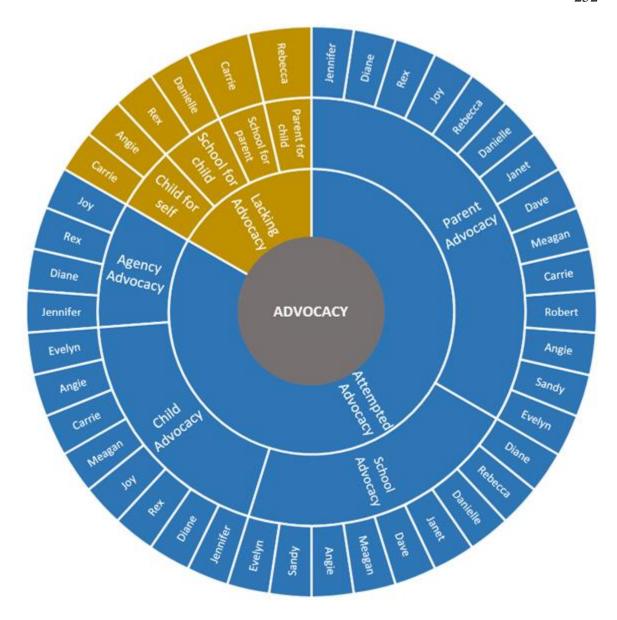


Figure 44. Theme of advocacy.

Parent advocacy. In the following two examples, parents advocate on behalf of their children with disabilities. In the first example, Jennifer's discourse reveals how her husband is a strong advocate for Luke, a child with a mixed-expressive receptive language disorder.

And that's what I love about my husband. He was in the meeting with us, and he is such an advocate and was able to just basically say, "Hey, listen. This kid can

bake all these kinds of recipes from scratch. He's a big helper in our home, he knows how to do laundry, and he knows how to use Excel. This kid has a lot going for him. And it seems like whatever we do with him should build on those strengths, rather than just overly focus on the weaknesses. (Jennifer, personal communication, July 1, 2017)

In the second example of parent *advocacy*, Janet reveals that it took considerable *advocacy* on her behalf to get the evaluation processes started for her daughter, Shawna, one of three triplets, a young girl with dyslexia.

But I had a benchmark. Like, I had, in my home benchmark. And what I was seeing with her, it wasn't even a progression, it was like, a regression. So, first grade I approached it, and nothing got done all year, and I brought it up several times. Well, well, nobody does anything. And then I got, I should have done this in first grade, but then again, I don't know that it would have helped.

But at the beginning of second grade, I wrote an email with this information. I am concerned with, plus, Teacher A was our second-grade teacher this year, and I could not say enough nice things about that woman. (Janet, personal communication, May 22, 2017)

Child advocacy. In this next example, *Rex* describes a moment when his daughter, Sierra *advocates* for herself. *Rex's* discourse reveals that even a child with limited communication, one who has a significant mixed expressive-receptive language disorder, can under necessary circumstances advocate for themselves. If the reader will recall the discussion on *Power via Expertise*, staff inappropriately handled Sierra at school. Sierra spoke up for herself in the only way a ten-year girl with a severe language disability can: "She would talk about school afterward as being a trap" (Rex, personal communication, June 24, 2017).

School advocacy. In this next example of *Advocacy*, Meagan's discourse reveals how a teacher can effectively advocate for a child providing support and opportunity.

Meagan is talking with April's teacher at Parent-Teacher conference. If the reader will

recall, April is receiving special education services for speech. April's teacher begins a crucial conversation with Meagan:

'Have you ever thought April is gifted?' And I was like, 'well, duh. Yeah. Yeah. I do think she's gifted. Absolutely. But she didn't pass through for the testing, and so I don't know how the process works.' And she took me by the hand and said, 'We need to sign a form, and we're going to put a committee together. And we're going to get her gifted tested [testing for gifted and talented].' (Meagan, personal communication, May 22, 2017)

Agency advocacy. As another example of *Advocacy*, Diane's discourse reveals how *Agency Advocacy* can reduce stress and improve comfort for a parent. Diane is talking about the transition from a birth-to-three program to the school district: "And then, they hand delivered us to the school district with her, so that was beautiful. Um, and pretty slick" (Diane, personal communication, July 6, 2017).

Lacking advocacy. Carrie's discourse, on the other hand, reveals two instances of Lacking Advocacy. The first instance regarding her son, Max in eleventh grade. She states, "He's so lost that he doesn't know which part of it he didn't understand" (Carrie, personal communication, May 24, 2017). In other words, if one doesn't know what they are missing, or don't know what they don't understand, then expecting that individual to ask questions in class or seek help for clarification or misunderstanding, is an unreasonable expectation. Simply put, Max is unable to advocate for himself and teachers that expect him to do so are asking too much. Carrie explains this as she recalls a conversation with the special education team.

'If he would just do this, that, the other thing.' And I just kept telling them. 'he can't do that. He doesn't do that. He can't. I don't know why because we haven't ever gotten to the bottom of it. But he can't do that. So, you keep saying just pay attention. He can't. You keep saying just ask questions. He doesn't know what question to ask. He's so lost that he doesn't know which part of it he didn't

understand.' (Carrie, personal communication, May 24, 2017)

In Carrie's second instance of *lacking advocacy*, Carrie refers to how she advocates for Max and advocates for other parents as they progress through the special education process. Carrie's discourse reveals why advocacy is important: "Yet as a parent in the process, I didn't have anybody there standing up for me, and it was a lonely place to be" (Carrie, personal communication, May 24, 2017).

Dignity

A fourth clear theme that arose from the discourse of eleven of my 14 participants was *Dignity*. *Dignity* is a quality. It refers to a state or quality of being worthy of honor, respect, or self-respect. The 11 participants revealed they or their children with disabilities gained dignity or lost dignity (see Figure 45). In Figure 45, Dignity, the theme is at the center, the subthemes, Gaining and Losing Dignity are the subthemes. The next ring contains the codes that contributed to each subtheme. And the outside ring involves the participants who contributed to each code.

In Chapter, II, Literature Review, I discussed literature surrounding the uncovered theme, *Dignity*. For example, I reported that the United Nations considers dignity a basic need of humankind, that all individuals are equal in dignity and entitled to both human and civil rights (United Nations, n.d.). In that review, I also reported authors who found this vision to be lacking for children with moderate to severe intellectual disabilities (Pennington et al., 2016). Moreover, I noted that other authors described instances of abuse, isolation, segregation, squalor, and an object of discrimination for these children (Griffiths et al., 2003; Horner-Johnson & Drum, 2006; Ward & Stewart, 2008). On the

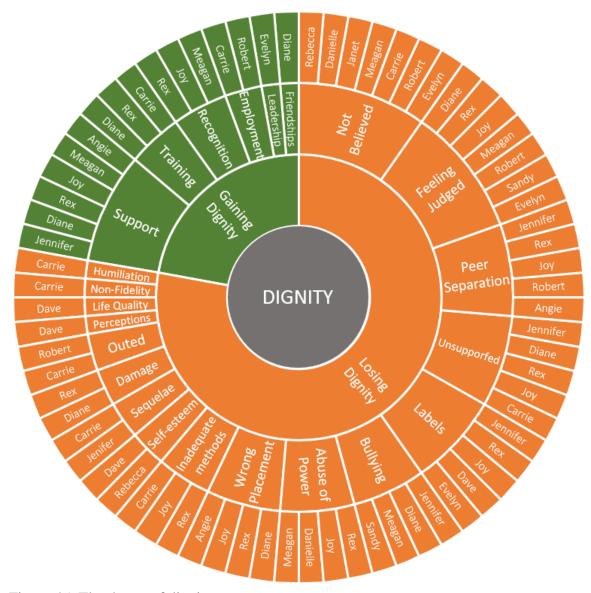


Figure 45. The theme of dignity.

positive side, I discussed Hodge (2015) who had discussed that many schools are attempting to provide dignity to children with behavioral issues through embracing approaches to positive handling. I added through discussion from Pennington et al. that "schools must provide environments in which students are treated with dignity" (p. 296). In this discussion, these authors provide a list of what seems like obvious ways to

communicate respectfully with others, and I provide it for the reader's benefit. In the following sections, I discuss the discourse that revealed how participants or their children with disabilities *Gained Dignity* or *Lost Dignity* in the context of the special education process. For example, the children with disabilities *Gained Dignity* through employment opportunities, friendships, leadership, recognition, support, and training. I present a sampling of this *Gaining Dignity* data in the following sections.

Employment opportunities. Two participants, Carrie and Robert, revealed their concern for their children with disabilities concerning employment. Robert, whose son Thomas has autism, seemed hopeful about his employment prospects. In his discourse, Robert refers to the *Rising Tide Car Wash*, a Florida-based business that trains and hires individuals with autism. Its social mission is to empower individuals with autism through employment. And one goal of the business is to have community members see autism as a diversity issue rather than a disability issue—which is a value to employers. As such, most of the employees at the *Rising Tide Car Wash* are individuals with autism. Robert's facts are a little hazy, but he recalls a story that he had heard 2 or 2 years ago:

Yeah. It's, I, I remember, there was this podcast a while back, and it was a guy who had started a business. I mean he was a business major, his uh, younger brother um, had Asperger's. And you know, he'd been, they've been trying to like what can we do with this kid? He's getting ready to graduate, you know, what's he going to do? And you know, the guy in the course, his research, he, he found out about how, these people with Asperger's, you know, once they graduate, so many of them tend to just spend all their time playing video games, and they lose all the skills that they have learned. At that age, it's like it's really difficult to get it back. So, he um, he's a business major, he brought this, there's this car wish, I think it was in like Boston maybe, this car wash, it was just nobody was coming to it. It was just losing money hand over fist.

He bought it for like \$12,000, some ridiculous amount and, and he um, hired; I don't know, I think like 60% or something like that of, of his workers are um, on the spectrum. You know he starts, they, they come in and um, their first job for

like the first couple weeks is they have to greet the customers that come in, make eye contact, say hi, I'm so and so. Um, we're taking care of you today. If you want to have a seat over here. And they have this script that they have to follow, but since after you know, a week or so, they start getting chatty. They start to want to talk to people. And he said that they, they loved this place so much that they'd come and hang out in the break room on their day off. And you know, hearing about that, I had not heard a thing about this you know, this regression before but, but hearing about that, we can help these kids be productive members of society. (Robert, personal communication, May 8, 2017).

Friendships. Diane's discourse reveals the challenge of having a child with multiple disabilities who is approaching adulthood. She is discussing dignity through employment, friendships, and independence regarding her daughter Maddison and mostly the friendship-social aspect of dignity:

She is 17. She is 18, September 27th of this year. She will be 18. She still doesn't drive. Never had a job. Has no friends. Has no social. The scary [part] for me is the [that she will] self-implode with the next phase [of life if] we can't hand deliver something. (Diane, personal communication, July 6, 2017)

It is scary for Diane because Maddison has already attempted suicide and it took a year of counseling services to move beyond that event. She believes that any one of these factors would help Maddison's *self-esteem*, *independence*, and *dignity*. Diane recalls an earlier time.

And she did some social [activity] with the XXX group for a while, but she had outgrown them which is sad because when it first started she was--it was shortly after the autism diagnosis--so maybe like 14ish. She came home and cried, she was like, 'it was the first time I've ever been able to be myself, and it was okay.' And it served a great purpose for a long time, but she is not intellectually disordered, so she has outgrown that social piece.

Leadership. Evelyn's discourse reveals *Dignity through Leadership* as she discusses her son Sam and Boy Scouts. Same is now a 'Star Scout' and has reached the "Life" award and has taken on the role of S.P.O. Evelyn says, "Yeah, he's the SPO right

now, so he's taken on a very more interactive role, leadership role than..." Sam interrupts, "In charge of it!"

Recognition. Meagan's discourse, on the other hand, reveals *Dignity through recognition*. Meagan is talking about April, her oldest daughter who has a classification of Speech-Language Impairment. In addition to an IEP, April also has a health plan in place with the school due to a food allergy. Meagan is talking about how the simple act of recognition can bring a sense of *self-worth* to a child with a disability:

She loved it because she loves that—this is a child who has food allergies. She has an EpiPen. She loved that her picture was in the nurse's office. That just made her so happy that she was one of their EpiPen kids. So, she enjoys that kind of recognition.

Support. Angie's discourse reveals multiple instances of *Dignity through*Support, the provision of scaffolding so that those who need it can achieve success.

Angie is the mother of Thomas and Timothy who both require a considerable amount of support for success to be evident. These support structures, however, are the starting point for *equity* and *dignity* for both children.

In the first example, Angie is discussing Thomas's special education teacher. Her discourse reveals that she would rather have Thomas go to a school farther away that has the necessary supports than have her son attend a school right across the street that does not provide what Thomas needs:

This particular guy, his son has autism. Maybe he is more tuned in. Thomas is in a program for kids with autism. Thomas does it. I do not know other districts that do it this way. Maybe there are a lot. They have a track. They have a program for kids with autism. We live right across the street from XXX High School, but he goes to XXX High School because that is where the program goes. People are like that is not okay. I am okay with that because then he is getting the support he needs from, in theory, staff that has been trained with extra training on autism.

(Angie, personal communication, May 8, 2017)

I then ask Angie if she believes special education is helping her children. Angie's discourse again reveals that support is crucial, "That is the golden question. I think overall yes. Could it be better? Yes of course. Could it be worse? I do not think either one of my kids would be successful just left to their own devices" (Angie, personal communication, May 8, 2017).

Training. Carrie's discourse briefly touches on *Dignity through Training*. She is discussing Max's future. I ask about an online college or if that would be too much for him.

I think that would be harder. I honestly think Max is extremely aware of his strengths and weaknesses. Because we've been talking about it since he was in fifth grade. He said something really profound just a month or so ago. He said, 'I learn best by doing things with my hands, and I haven't done that in a really long time.'.... So, I think a vocational training program is a way to go. (Carrie, May 24, 2017)

A Vocational Training Program would give Max the structure, support, and training to be successful with his hands which would lead to *Dignity through employment opportunities*.

Losing Dignity

The participants whose discourse revealed methods of gaining dignity as discussed above, spent more time, however, discussing how their children with disabilities *lost dignity* (refer back to Figure 45). That is, the discourse of my participants revealed how their children *lost dignity* by *feeling judged*, by perceived *inappropriate* placement of the child with disabilities, by not *feeling believed*, by feeling *outed*, through

perceived abuse of Power, bullying, labels, lack of fidelity, exclusion, and through sequelae of impairment.

Feeling judged. Sandy's discourse is full of *Feeling Judged*. As I re-read and listen to the audio recording of Sandy again, I sigh each time and think, it shouldn't be like this. Sandy is talking about the special education process meetings regarding her daughter, Chelsea who has multiple disabilities:

It felt like I was talked down on, looked down on like I wasn't doing my job like I was reading to her. It was always like, kind of like it was my fault, like, 'It's your fault, mom. You're not reading to her; you're not teaching her, you're not showing her anything. You're probably just putting her in front of the television and ignoring her.' This is how I felt, and that's not me at all. I've done all of the things I've done with my boys, and I do them even more so with her, and I even had them with her many times and just work with her with what they were learning, and stuff and it just wasn't the same.

It was saddening each IEP where it's new people again, and you feel that same, 'Oh, they're judging me again,' or the new teacher that's like, 'Oh, she is so delayed. The mom must not pay any attention to her,' again and it's just like, 'You don't know my daughter.' (Sandy, personal communication, April 6, 2017)

Inappropriate placement. Joy's discourse revealed Losing Dignity through Inappropriate Placement as she talked about her daughter Sierra:

There were kids in there that had very specific needs that were just on like learning to live. Like feeding yourself. Kids were still learning to be potty trained. Other needs that were more severe and less about reading and math and making sure that you can take care of yourself during the day. And that wasn't a great spot for her, and it was just utter chaos in there. (Joy, personal communication, June 24, 2017)

Not believed. Danielle and Janet's discourse revealed *Losing dignity through Not Being Believed.*

Danielle's discourse revealed *not being believed* as she discussed a nuance between special education and gifted education: "I said," it is law. It is mandated.' They

said, 'No. It does not apply to the gifted children.' Close quote. Not exact quote, but 'That is not for the gifted children.' Yeah. Six months after request.

Janet, on the other hand, stated, "Yeah. So, it's frustrating. And I feel like people don't believe me. I felt like I sounded like the hypochondriac mother" (Janet, personal communication, May 22, 2017) as she discussed trying to get help for her daughter *Shawna*.

Outed. Robert and Carrie's discourse each revealed an instance where their children were outed in front of their peers. Robert recalls an instance with Thomas, his son with autism who are at an assembly in a gym:

He's whacking another kid on the head. So, all right, that's the type of thing: 'Hey!' This is a great learning opportunity. It's a loud noise, in places very sensory you know, stimulating. Why don't you sit further back here and then you could observe them and comment? You don't have to call him out right now, but you can talk about it the next day. But no, she didn't. (Robert, May 8, 2017)

Similarly, Carrie recalls how her son Max *loses dignity* and is *humiliated* in front of his peers from the actions of his art teacher, "And the art teacher stopped him in front of the class and said, 'no, no, no. This is all wrong. You're not doing this right. Just go sit down." (Carrie, personal communication, May 24, 2017).

Abuse of power. Four participants discuss how their children *Lost Dignity* through Abuse of Power. Rex and Joy's discourse reveals how a teacher potentially caused physical and emotional trauma to their daughter, Sierra. Rex began, "So, we had a substitute Special Ed teacher who kind of screwed things up too because he was...."

Joy, chimed in, "Terrible."

Rex continued:

He was, I think he was retired and he'd come out of retirement to help out as a substitute teacher. He reminded me of my dad. Where my dad thinks that Sierra's problem is something that she can just overcome with her will which is not the case. So that guy was kind of that way. He was more hands-on, like physical. We had to tell him like, 'don't put your fucking hands on our kid.' Like, 'don't do it.' He was confining her, which may be emotional, or it may be physical. (Joy and Rex, personal communication, June 24, 2017)

Meagan's discourse also revealed loss of *dignity* resulting from the *abuse of Power* that causes physical and emotional pain.

They had the children do wall sits on the first day of PE. The first day of PE, they wall sat for 20 minutes. She's a championship Irish dancer, so she's used to physical activity. She couldn't walk for two weeks. Her legs—she has a Pilates instructor she was working with. Her legs were so damaged that her muscle had no jiggle. It was solid. She couldn't bend down to her locker. We had to carry her to bed. So, it wasn't like this had anything to do with, oh, middle school is overwhelming. This was physically [abusive]. She was in pain. And then, mentally she was in pain because nobody seemed to care. The teachers laughed about it. They thought it was a big joke that the 6th graders couldn't walk. (Meagan, May 22, 2017)

Bullying. Four participants revealed or mentioned *bullying* in their discourse. In schools, bullying is unwanted, repeated, aggressive behavior among school-aged children. It involves either a real or perceived power imbalance. Jan and Husain (2015) and Williford et al. (2016) discussed the negative effects of being bullied. These researchers stated that many negative outcomes, including impacts on mental health, substance use, and suicide link to bullying. These investigators noted that this includes increased instances of depression and anxiety, increased feelings of sadness and loneliness, changes in sleep and eating patterns, and loss of interest in activities that those who are bullied used to enjoy (Jan & Husain, 2015; Williford et al., 2016). These authors noted that these issues might persist into adulthood. Moreover, Boyle (2015) and van der Werf (2014) found that children who are bullied experience decreased academic

achievement with both GPA and standardized test scores, as well as a decrease in school participation. They are more likely to miss, skip, or drop out of school.

April, Dave and Meagan's daughter, met the definition of a bullied child. April is a child with a speech disability (a lisp). In the following discourse, Dave discusses April: "And there was a lot of jealousy because she was coming in as a freshman doing well, so one girl, in particular, started bullying her by mocking her lisp" (Dave, personal communication, May 22, 2017). He then returns to this thought a short time later.

It was interesting because she had been bullied by this girl. And we had her [April] documenting it. I'm like, just document it. I know the school's not going to do anything, but document it, and once we get enough, we'll bring it in. So, we've been documenting it, and the girl cyberbullied her. So, we documented it. (Dave, personal communication, May 22, 2017)

Dave then talked about what they did with the documentation.

When we took it to her teacher, it was 'What? She's being bullied?' And so, April went over everything that was happening, and she said, 'The principal's going to want to know about this.' (Dave, personal communication, May 22, 2017)

Labels. Four of my 14 participants (28%) revealed a concern for *Labels* in their discourse. Labels are referential devices that can be 'helpful' or 'unhelpful' dependent upon one's ideology (Lauchlan & Boyle, 2007). These researchers categorize arguments for and against the act of labeling with a 'helpful' and 'unhelpful' dichotomization.

Gillman et al. (2000), for instance, argued that a label—a diagnosis—leads to services; it provides an avenue to resources. On the other hand, Archer and Green (1996) argued that a label can be helpful if it leads to some interventions that are specific. However, Archer and Green noted that special education professionals might push for labels that provide schools with extra funding, lacking consideration for the child's individual programming

needs.

A separate helpful-unhelpful ideological argument for labeling is that on the one hand "labeling leads to awareness raising and promotes understanding of particular difficulties" and on the other, "labeling leads stigmatization" (Lauchlan & Boyle, 2007, p. 37). Lauchlan and Boyle discussed *awareness* and *understanding* as they referenced Gross's (1994) explanation. Gross wrote that increasing awareness "may lead to increased adult tolerance...that helps teachers, and care[taker]s understand why the child [has particular difficulties]" (p. 105). Gillman et al. (2000) counter that argument, however, by stating that individuals may be disadvantaged socially and excluded. That is, labels may lead to social disadvantage and exclusion from conventional society. At the same time, divergently, Riddick (2000) contended that stigma might precede or occur in the absence of a label.

A third perspective on labeling according to Lauchlan and Boyle (2007) is that they "reduce ambiguities and provide clear communication devices for professional exchanges of information" (p. 38). However, these researchers noted that "there is no clear agreement on how labels are decided" (p. 38). The *Diagnostic and Statistical Manual* (DSM) exemplifies this issue. The manual gives precise information regarding diagnoses so that professionals can exchange information and have a common frame of reference. In my experience and practice as a speech-language pathologist, however, each update to the manual's diagnostic criteria has created confusion for professionals and parents, particularly the later. For example, criteria for autism and Asperger Syndrome changed in the revision from the DSM IV manual to the latest version, DSM V:

'Asperger Syndrome' was absorbed by the diagnostic category 'Autism' and autism is now seen through a lens of severity, a continuum of deficits from mild to profound. In my experience, this change angered parents who did not want the 'autism' badge placed on their child. Kite, Gullifer, and Tyson (2013) support these clinical observations. These researchers confirm an increased stigma associated with the autism label. They reported that 89.7 of their sample believe there is a difference between the disorders. Their analysis showed participants believe that the autism label has a significantly greater impact on the child than Asperger's Syndrome (z = 9.1, p. = 001, two-tailed; r = .41 two-tailed) and on the family (z = 10.61, p = .001, two-tailed; r = .48). Half of their participants were opposed to the change.

The fourth dichotomy for labeling reported by Lauchlan and Boyle (2007) is that they "provide comfort to children and families by 'explaining' their difficulties" (p. 40). Lauchlan and Boyle stated that labels, however, can lead others "to focus on within-child deficits and possibly lowered expectations" (p. 40). And the last dichotomy for labeling reported by Lauchlan and Boyle (2007) is that "labels provide people with a social identity: a sense of belonging to a group" (p. 40). The counter-argument to this is that "labeling can lead to teasing, bullying, and low self-esteem" (p. 40). (See *Bullying* under *Losing Dignity* above for a discussion of effects.)

Rex's discourse on labels reveals much of the criticism on labels investigated Lauchlan and Boyle (2007). In his opening statement, Rex brings up the first two label criticisms dichotomy (*opening doors to services* vs. *just wanting appropriate services* and a label defines one's life):

The diagnosis was a hang-up for sure. At the time it was just, we wanted *Sierra* to be able to have the opportunity to talk. You know what I mean? Like before we, I feel like a diagnosis is and I'm sure you've heard this too, but a lot of parents think if you get the right diagnosis, you get services. So, I know I have a lot of people I've talked with is they want an ASD diagnosis because they feel like that opens doors. But I don't want Sierra to feel like.... I feel like if you get a diagnosis, that's your life. (Rex, personal communication, June 24, 2017)

Rex then proceeds to confirm the research by Kite et al. (2013).

And I don't want *Sierra* to carry a heavier diagnosis or something that's wrong that's going to carry through her education and her life. I wanted...and I guess we have.... I know the spectrum had changed a lot and we maybe are more conservative. We're looking at more classic autism. Where we wanted to give *Sierra* the opportunity to develop speech before we gave put that heavier diagnosis on the rest of her, like the social capabilities and everything else. When you can't talk, it's very hard to be social. So, we wanted to give her that opportunity before we gave her what feels like a heavier diagnosis. We just wanted to give her more time to develop speech and then if speech never came or if socialness never came, then we could change. (Rex, personal communication, June 24, 2017)

Evelyn did not want her son Sam to receive the autism label either. She too believes the *label* carries with it a life-long burden.

He has kind of—he is on the autism spectrum, but we haven't had him fully diagnosed. My father-in-law is a child psychologist who diagnoses autism in children and so when we moved here, and he had more interaction with Sam, it was, 'Yeah, he's on the autistic spectrum. If you want to get him in, I can tell you the right things to do.' I said, 'You know what? I don't know that I want to *label* that.' I said, 'That gives a different connotation when you talk to a person, and I don't want him labeled that the rest of his young life or adult life.' I said, 'He may be, but we'll work on it without the *label*.'

So that's why I didn't want him *labeled*. And he has kind of awkward situations with peers. There's a lot of—until he got into Boy Scouts out here, it was very awkward situations. He was always well-versed talking with adults, had no problems talking with adults. But children his age, he had issues with. As he's gotten older, he's learned to deal with social situations like that but more—more of like, "I know I'm supposed to do this," rather than, 'This is enjoyable for me.' (Evelyn, personal communication, April 7, 2017)

Dave, the father of April and Heather, talked about the negative connotations of

labels as well. As his daughter has the classification of "twice exceptional" (Dave, personal communication, May 22, 2017), he tries to focus on the categorization of Gifted.

Yeah. I'm worried about the way she perceives that. We focus on the gifted part of it...because she asked us, she came in yesterday morning, and was like, when I get this fixed, my clutter, will that change my personality? (Dave, personal communication, May 22, 2017)

Jennifer also reveals her concern with labels in her discourse when discussing her son, Luke, a 14-year-old child diagnosed with a mixed expressive-receptive language disorder. Jennifer justifies not labeling her child with autism based on her belief of how a child with limited language would interact with the world.

And so, you could say all the rigidity that—my issues are not disputing autism or not, but he did have—someone who has a limited understanding of the environment is going to be a little more rigid because they don't otherwise have ways to negotiate the nuances of their environment. (Jennifer, personal communication, July 1, 2017)

Lacking fidelity. Fidelity in education is the adherence to a program, curriculum, or procedure. My participants reveal instances where the special education process is Lacking fidelity. In the examples below, this Lack of fidelity led to humiliation, failure, and a loss of scholarship funding, all of which lead to a loss of dignity.

The literature demonstrates that a lack of fidelity for special education students is problematic. For instance, VanSciver and Conover (2009) reported that "research has shown inconsistency in teachers' knowledge and assignment of accommodations" (p. 3). More recently, research on implementation has demonstrated a variety of barriers to the application of evidenced-based practice (EBP) in general education classrooms for students with disabilities. These barriers include lack of resources, staff, and adequate training (Cook et al., 2014; Russo-Campisi, 2017). "As more researchers investigate

issues with implementation, it is becoming clearer that the research-to-practice gap continues to persist despite the accurate identification of EBPs for students with disabilities (Russo-Campisi, 2017). VanSciver and Conover reported that failure to implement accommodations with fidelity occurs at three levels: the paper implementation level, the procedure implementation level, and the process implementation level. Below, I briefly discuss each of these levels.

As an example of the *Paper implementation* level, Ketterlin-Geller, Alonzo, Braun-Monegan, and Tindal (2007) reported that tracking systems are notably absent. Tracking systems would help ensure that "appropriate accommodations are "being assigned and that these accommodations are consistently being applied to classroom instruction and assessments" (p. 195). At the *Procedure implementation* level, however, Wallace, Blasé, Fixsen, and Naoom (2008) stated:

The problem is that not much of what goes on is functionally related to the new practice. Training (such as professional development days for teachers) might consist of merely didactic orientation to the new practice or program, supervision might be unrelated to and uninformed by what was taught in training, information might be collected and stored without affecting decision making, and the terms used in the new innovation related language may be devoid of operational meaning and impact. It is clear that the trappings of evidence-based practices and programs plus lip service do not equal putting innovations into practice with benefits to students, schools, and communities. (p.15)

Concerning *Performance implementation*, VanSciver and Conover (2009) discussed the work of Paine, Bellamy, and Wilcox (1984) and stated that at this level, innovations are put into place so that faculty can attend to core interventions with fidelity. As an example, Ketterlin-Geller et al. (2007) questioned whether accommodations are being provided consistently by general education teachers. They noted that special

education student achievement depends on the regular, consistent implementation of accommodations.

Carrie's discourse about *Max* reveals how a general education teacher's failure to follow written IEP accommodations with fidelity can result in *humiliation* and *loss of dignity*. It appears in Max's case that the failure was one of *Performance implementation*:

The teacher handed him, at that moment, last day of school, the rubric for how the project was supposed to be done. He didn't have it up to that point. He didn't know there were other expectations. He didn't know it was supposed to be in written form. He didn't know that there were these five things that had to be covered. He didn't know any of that, and he got an F on the project because he didn't do it right. (Carrie, personal communication, May 24, 2017)

Diane's discourse, however, reveals a failure to implement accommodations at both the process and procedure level. In other words, the teachers' *inability* to understand the process and implement the procedure with fidelity resulted in the *loss of dignity* for Maddison. Maddison experienced unnecessary failure, the loss of scholarship opportunities, and it put the family into a situation of financial hardship. The family does not know how they are going to afford Maddison's higher-education tuition when she graduates.

I made a point; I special met with them three times to make sure, because all I really cared about, was her accommodations for her ACT. She is bright enough to go to school, but we just have to have that extended time to do the different sections and that kind of thing. So, I met with them twice as the only major request. They completely botched it. They didn't get her. Apparently, the SLP turned it in, but the guy who had to do the final whatever is a resource teacher, didn't recognize her name, didn't see it, so he didn't submit it. So, she had to take the ACT without accommodations. That went straight to all red and not very nicely either. And so, they ordered another ACT and paid for it and, so we took it four weeks later with her accommodations, but it messed up three different or two different scholarships that were specific. She loves STEM and robotics and science and all that kind of stuff. One was specifically for someone with a disability and a girl in STEM. The other, and it was a ten-thousand-dollar

scholarship, and it had to be done while you were a junior. And then the other one was leadership and a girl and disability. She has run and done all her options for independent youth group. She has been an [XXX] adventurer for a 4H councilor. She has been an [XXX] mentor for the university for two years. So, she has got 'leader.' So she has all these things, we couldn't apply for either of them because they messed up the ACT. So that was potentially fourteen thousand dollars we didn't get. I hate high school resource because I'm qualified enough to do it (Diane, personal communication, July 6, 2017).

Exclusion. The concept of *Inclusive education* for children with disabilities centers on equal opportunity that garners an individual's right to an education. Inclusive education "develops...potential and respects...human dignity" (Peters, 2007, p. 99). Peters noted that inclusion goes beyond integration, the physical accessibility of classrooms or school facilities. Rather, Peters stated that the school system must furnish children with disabilities instructional support systems that are adequate (e.g., flexibility with curriculums (both quantity and quality), flexibility with instructional methodology, and a "welcoming school community culture that goes beyond tolerance to acceptance" (p. 99). According to the Ministry of Education and Science within the United Nations Educational, Scientific and Cultural Organization (1994):

Regular schools with this inclusive orientation are the more effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system. (p. 2)

Inclusion differs from "mainstream" or "integration" (Valente, Danforth, & Bank Street College of Education, 2016). With inclusion, there is a "commitment to school/community transformations and to collectivist strategies of difference and schooling" (Valente et al., 2016, p. 4). Valente et al. stated that mainstreaming and integration, on the other hand, are "timid approaches" (p. 4); these approaches simply

place children with disabilities into general education classrooms. Moreover, they keep the mores of the classroom in place; students with disabilities must shoulder their success. With mainstreaming and integration, schools eschew any reforms of their procedures, pedagogies, and frameworks (Boldt & Valente, 2014; Danforth & Jones, 2015; Slee, 2011; Valente et al., 2016; Waitoller & Thorius, 2015).

Genuine inclusion then involves a paradigm shift (Thompson, 2015). In discussing Ferguson (1995) and Thompson, Valente et al. (2016) wrote that with inclusion there are genuine reforms to the curriculum, teaching practices, and frameworks within a school. It involves unification and commitment from all stakeholders to value the "biological and cultural diversity of the school community" (p. 5). In IDEA, however, inclusion is not a requirement; rather, IDEA calls for children with disabilities to be in the least restrictive environment (LRE), a flexible IDEA provision. The flexibility of this provision means, as stated by Waitoller and Thorius (2015) that schools can conceive innumerable interpretations and misinterpretations as to what a child's true LRE *is* and how to appropriately execute it.

In this investigation, five participants (35%) reveal within their discourse the concept of *Exclusion from Others*. In the first example, Jennifer, the mother of Luke, a 14-year-old boy with a mixed expressive-receptive language disorder, discusses her son's *loss of dignity* regarding *exclusion* from peers. The speech-language pathologist is pulling Luke out of class for language-based therapy services: "So, he didn't know this was going to happen [at this particular time]. He didn't like it when they wanted to pull him out because he was enjoying himself, he was in the flow of learning whatever" (Jennifer,

personal communication, July 1, 2017).

In my second example of exclusion, Robert, father of Thomas and Timothy reveals the concept of exclusion from peers in general education at a basketball game: "They had an assignment to attend the school basketball game. And so, the teacher sat down in the front and all the kids with needs [were] especially way back in the very back, hidden by the General Ed kids" (Robert, personal communication, May 8, 2017).

In my third example of exclusion, Angie, mother of Thomas and Timothy also reveals the concept of *exclusion*. *Angie* is talking about the placement of special education classrooms in portables, particularly with children who are more severe (i.e., *Thomas*, a child with autism, mental health, and behavioral health issues): "They are always in the portables. It was always in the portable, all day long, in the same classroom with the same teacher. I am like, 'No'" (Angie, personal communication, May 8, 2017).

In my final example, *Rex's* discourse reveals *Exclusion* and *Loss of Dignity* as he discusses his daughter Sierra, a child with a severe expressive-receptive language disorder. Rex states, "I believe their agenda was [over-talk] to get rid of the disruption in class and so the regular classroom could proceed as they're supposed to, and Sierra could wither on the vine in the Special Ed room" (Rex, personal communication, June 24, 2017.

Sequelae of impairment. Two participants revealed through their discourse that their children with disabilities had *lost dignity* due to the *sequelae of their impairment*. As an example, Jennifer's discourse reveals that Luke, age 14, appears inappropriate for his age both with adults and with his peers when communicating. His *Loss of Dignity* is from overt behaviors that define his impairment.

And I think he stands out in terms of how his speech sounds, you might take him for a non-native speaker, or he might sound somehow like an alien visiting earth [chuckles]. I'm standing at the door the other day with some people, wanting to go over some details about a youth group. And he came home from scouts at the time, and he stood at the door and said, "Why are you talking to my mother at the door?" Which is, it was just how he said it that's just funny. Like your average kid at 14, wouldn't even refer to their mom. We don't expect him to call us "mother" and "father," but he does. [Chuckles] He's just sort of really—he gets along well, but he could use some training somehow—he speaks loudly, for example. That's one that could be a turnoff for some kids his age. (Jennifer, July 1, 2017)

Carrie's discourse, on the other hand, reveals *covert sequelae* that affect *self-esteem* and *dignity*. In the first instance, Carrie reveals *frustration*: "He doesn't even know that he's missing instruction sometimes. So, from that perspective, it was just a frustrating experience (Carrie, personal communication, May 24, 2017). Carrie then reveals more about his *covert sequelae*, "Max doesn't know that he's having an issue until somebody points it out to him" (Carrie). As the expectation at the High-School level is to advocate for oneself, Carrie rounds off this conversation with, "How can you ask questions when you don't know that you're missing information?" (Carrie).

Equity and Equality

In Chapter I, *Introduction*, I discussed equity and inequality from a historical and cultural context of special education. In that text, I referenced Chinn (2004) who discussed the parallels between the legal segregation of African American children (*Plessy v Ferguson*, 163 U.S. 537, 1896) and children with disabilities. I then discussed the supreme court case that purportedly ended segregation for African American children (*Brown v Board of Education*, 1954). I also discussed and court cases that eventually led to desegregation and laws designed to protect the rights of children with disabilities

(Pennsylvania Association for Retarded Children v Commonwealth of Pennsylvania, 1972; Mills v. Board of Education of the District of Columbia (1972); Education for All Handicapped Children Act (20 U.S.C.A 1400(b) (1975); Individual with Disabilities Education Act (IDEA), (1997, 2004); No Child Left Behind Act (NCLB) (2001, 2004, 2007; and Every Student Succeeds Act (ESSA, 2015).

Following this discussion, I then turned the readers' attention to the on-going challenges and recent evidence of inequity and inequality that remains for children with special education—the impetus and justification for this research project.

Within that introductory literature review, I described problems within the special education process that appear commonplace. I chronicled instances of cultural and linguistic hegemonic discourses that saturate equity and disability literature. Within that chronicle, I first explained how linguistic hegemony exists at a surface level and within the deep structure of that process. On the surface, I noted that linguistic hegemony is present within this process by what is explicitly said (e.g., jargon, acronyms, deficit-based discussion of children with disabilities). More deeply, however, I noted that linguistic hegemony is present by the inherent rules within the special education process framework. The inherent rules subordinate parents by default. Subordination occurs because of their 'layman' skill and knowledge regarding remediating the child's challenges. I then explained how cultural hegemony is omnipresent within the special education process because of its inherent power relationships: parents, who want their child to be like his or her peers appear to have little say in the process. For the most part, they defer obligatorily to professional opinion. I concluded this discussion, by stating that

within the context of the special education process, there are social norms that establish the social structures. Intentionally or unintentionally, these inherent structures are used by the ruling class (the professionals) to wield cultural dominance (the child's placement within the education system) and impose their worldview (the remediation program outlined in the IEP; Mouffe, 2000).

Regarding the results of this dissertation study, nine participants revealed instances of a desire for *equity* for their children with disabilities and six participants revealed instances of a desire for *equality*. Sun (2014) discussed both concepts. Sun stated that these concepts are two strategies one can employ to produce fairness: that is, when equity occurs, everyone has what they need to be successful; equality, on the other hand, is the act of treating everyone the same. Equality aims to promote fairness; it can't occur, however, if not everyone starts at the same place or needs the same help. On the surface, equity seems unfair, however, by employing equity everyone moves closer to success by receiving an equal opportunity. The challenge with equity is that "not everyone starts at the same place, and not everyone has the same needs" (Sun, 2014). See Figure 46 for illustration of thematic results. In Figure 46, the Theme *Equity and Equality* is the center. The next ring, the subthemes, include *Equity, Inequity, Seeking Equity*, and *Seeking Equality*. Outside of the subtheme ring are the codes that comprise each subtheme. The Outer edge contains the participants who contributed to each code.

Equity and equality. In Chapter II, Literature Review, I discussed through Kozleski and Smith (2009) and Sun (2014) how achieving equity within a school system is a genuine challenge. Kozleski and Smith identify 20 factors that need to be considered

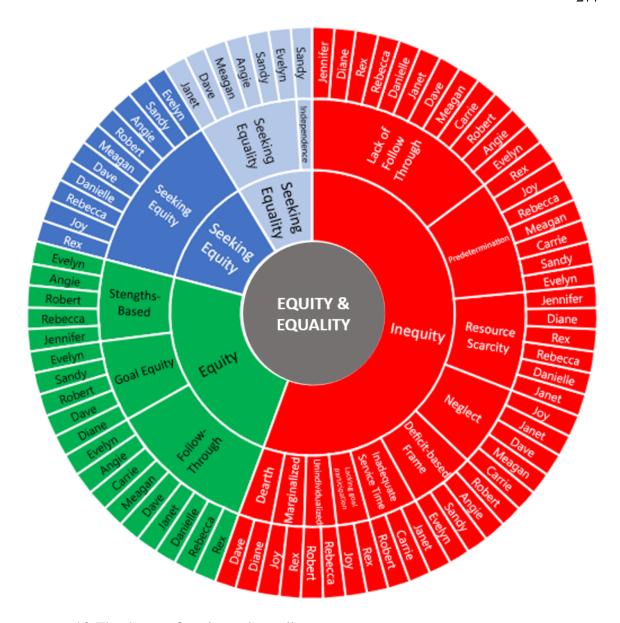


Figure 46. The theme of equity and equality.

to make an effective change (I encourage the reader to refer to Figure 3). Organizations, such as school districts, must systematically change these factors. Moreover, as stated simply by Sun, the needs and starting place are never the same for children with and without disabilities.

Angie discusses *Equity* as it relates to a Free Appropriate Public Education

through IDEA (2007). In this southwestern state, Angie is seeing preschool-aged children take a year to get through the testing and qualification process. She sees it as an injustice for these young children who have lost a whole year of support. Angie is just a practitioner, but she is asking questions aloud from an ethical standpoint.

That is a crime. I mean this year I work and part of my time I spent at XXX where we are doing transitions from birth to three into preschool. I have kids that I tested in September and October that were just having their meetings now [May]. *Is this like okay?* Those are kids that were probably identified through the XXX screenings and not necessarily transition kids. Still, it is like why is it that it is taking so long to get from the testing to when we have the meeting and have eligibility determination? Is that not kind of ridiculous if a kid qualifies? It took us a whole school year. We have lost a whole school year of support for these kids. (Angie, personal communication, May 8, 2017)

In this next example of *Equity*, Danielle reveals an instance of the theme *Equity* in her discourse. It emerged during a discussion of fairness she had with her fifth-grade daughter regarding the testing process. The daughter felt bad for her brother, Sam, because he did not qualify for services at that time.

We talked about how the testing process, seeing if they can qualify is a *moment* [emphasis added], and it needs to be a perfect snapshot, but those do not happen, but rarely. Sometimes they will have a smudge, or everything is focused in the picture except for your hand, and that is blurry, so you cannot use that picture for the family photo. Maybe what has happened to *Sam* is, maybe he had just a blurry spot. No, it is not fair, but they have to have the rules somewhere. You have to have that somewhere. When a fifth grader can recognize it, maybe we should fine-tune. (Danielle, personal communication, May 25, 2017)

Meagan reveals an instance of *Equity* when talking about her oldest daughter,
April. Speech and language therapy has helped her daughter, which she had a right to due
to being found eligible for a significant speech delay. The *Equity* comes from the *freedom*from bias possibility that will potentially occur in the fall. Megan says, "So anyway, [we]
got the therapy started. She's in therapy. She's doing exceptionally well. The Speech-

Language Pathologist thinks by the beginning of next year that she'll be out of speech therapy" (Meagan, May 22, 2017).

In my last example of *Equity*, I present Carrie's discourse regarding her son Max who is in eleventh grade. Briefly, Max has a Specific Learning Disability that crosses language processing, comprehension, reading, as well as oral and written expression. Carrie's discourse, however, reveals an instance of *Inequity*. It reveals *injustice* and *bias*. Carrie begins the story talking about high school level language services which are 'consult-only' as opposed to 'direct therapy services.' In other words, the speech-language pathologist servicing the school occasionally checks in with the student.

"Hey, how's it going? Good? Okay, fine." And they walk away. Because *Max* doesn't know that he's having an issue until somebody points it out to him. And the example of that is the very last project he was supposed to do in art class. He excels at art. He's really good at art. That's something he's really good at, but the project involved not just creating this sculpture, but writing a proposal for somebody to build it in a public place in the community.

So, it's a paper project, not an art project. And he got up in front of the class with his little project, his three-dimensional sculpture. Started describing what it was and how he would try to talk somebody into doing that out in the real world. And the art teacher stopped him in front of the class and said no, no, no. This is all wrong. You're not doing this right. Just go sit down.

[The teacher] humiliated him in front of the class. He told me when he came home, he felt like throwing the pot on the floor and running out of the room. But he knew that would get him in trouble, so he didn't. He just sat in his seat with his head down and just escaped into his own thoughts. Tuned out, didn't hear anything else that went on that day.

The teacher handed him, at that moment, last day of school, the rubric for how the project was supposed to be done. He didn't have it up to that point. He didn't know there were other expectations. He didn't know it was supposed to be in written form. He didn't know that there were these five things that had to be covered. He didn't know any of that, and he got an F on the project because he didn't do it right.

How can you ask questions when you don't know that you're missing

information? (Carrie, personal communication, May 24, 2017)

As Max's needs are invisible, this story reveals a clear case of *inequity* and *bias*. It reveals that Max's art teacher cares little about Max, at least not enough to read his IEP goals or be aware of accommodations specific to assignment or instruction modification, such as providing a rubric so that Max can follow and complete assignments appropriately. In this example, Max's disability is *outed* by being told to stop and sit down, a form of *humiliation* in front of peers. This detail exacerbates the *injustice* and *inequity* within Carrie's discourse.

As an example of *Equality*, Sandy 's discourse about her daughter Chelsea—the 9-year-old girl with multiple disabilities—reveals a chance for independence, being more like that of her peers. Sandy is discussing the simple act of leaving the classroom on one's own and going to where she needs to go, *independently*. She compares last year to this year.

So, it doesn't seem to be a problem, and it's giving her sort of independence to like, "Oh, I get to go to another classroom." Like, last year, she'd wander off. She would go hang out in the bathroom, and she'd go to the office and the nurse's station. But this year they haven't had any issues with that. She is going where she needs to go, and she has a little independence. So, this IEP, it's very similar to the last one because she is not—she is progressing, but she is not making huge gains (*Sandy*, personal communication, April 6, 2017).⁶

⁶ Following this comment, I engaged Sandy in some coaching. She wanted more for her daughter, to make her feel more 'equal,' to have faster progress, perhaps more flexibility in teaching methods ('maybe there is another way to present things to her' (Sandy, personal communication, April 6, 2017), or additional speech therapy time. Sandy struggled with my suggestions. She said, "actually don't feel comfortable asking for more so I feel like I would be a burden to have to call everyone back together but it's my daughter so to heck with them' (Sandy). I explained that communication with the team would alleviate some of her anxieties. That it, at the very least, wouldn't hurt and that she might be surprised by the result. With Sandy, I accomplished my primary, short-term goal of this project which is to support and empower parents of children with disabilities

Voice

A sixth theme that emerged from the discourses of my 14 participants was *Voice*. When I use the term voice, I refer to the sense of identity within an individual. *Voice* is the ability to express a personal point of view. *Voice*, in my view, affords an individual to engage and respond to others, a topic, or a discussion. It enables a sense of belonging and well-being. *Voice*, then, in the context of this dissertation, is having an acknowledged place within the special education process; this acknowledged place actively removes parents from that of 'observer' or 'form signer.' It is the full acknowledgment, acceptance, and inclusion of a parent as an equal team member, and thus an *equal voice*. The special education process, then, is a forum for parents who have children with disabilities to express ideas in a clear, coherent way, because others and the parent understand that one's thoughts and ideas are important. As stated by McElroy-Johnson (1993):

Voice is identity, a sense of self, a sense of relationship to others, and a sense of purpose. Voice is power —power to express ideas and convictions, power to direct and shape an individual life towards a productive and positive fulfillment for self, family, community, nation, and the world. (p. 86)

In this dissertation study, eight participants revealed instances of where they felt like they had a voice when communicating within the special education process for their children with disabilities. Ten participants, on the other hand, revealed instances of where they felt like they did not have a voice when communicating within the special education process for their children with disabilities. See Figure 47 for an illustration of the theme *Voice*.

In Chapter II and Table 6, I discussed the literature related to the theme *Voice*. For



Figure 47. The theme of voice.

example, Kaczkowski (2013) identified a lack of voice for both children with disabilities and the parents of children with disabilities. I also discussed the work of MacLeod et al. (2017). These investigators reported that "parents continue to feel like outsiders" (p. 382). They also presented that research on this perception includes the notion that

"teachers continue to feel underprepared to understand diversity as it pertains to families with students with disabilities" (p. 382, citing Hansuvadha, 2009; and Houtenville and Conway, 2008). Other researchers, however, described how parents who voiced their "intuitive advocacy" (knowing their child best) during the special education process, did not always obtain "positive outcomes for the mothers and their children" (Stanley, 2013, p. 208). Stanley noted that administrators "disregarded this type of information, thus impeding their advocacy efforts" (p. 208). In the following sections, I discuss the discourse surrounding my participants when they felt as if they *Had Voice* and when they were *Lacking Voice*.

Have a Voice. In Chapter II, and in Table 6, I discussed literature surrounding Voice. As noted, the discourse of eight participants revealed instances of having a Voice during meetings within the special education process. For the survey, about half of the participants indicated that they had a voice during these meetings. In other words, school-based team members listened and gave credence to a parents' perception, opinion, or request. MacLeod et al. (2017) noted that parents perceive the concept of Voice during the special education process when teams treat parents as partners and when teams use a strengths-based lens and explain ideas and policies. Moreover, the perception of Voice occurs when teachers are flexible, indicating that they are willing to learn and try new things. I present examples of my participants having a voice below:

In the first example, *Angie is talking about a wish she had with her son Thomas*, so, she voiced it at an IEP meeting.

I was like why can my son with autism not be in a general education classroom with an EA? He has average IQ. He has the ability. Why can he not be in a

general education classroom with support? His case manager goes I can make that happen. He did. He was able to be. In January last year, he switched to two general education science and social studies. That case manager was like I am going to be right there with him. I am going to help him manage his behaviors and be able to get the curriculum. They are out there. You know? They are few and far between, but they are out there. (Angie, personal communication, May 8, 2017)

In this next example, Jennifer ties the themes *advocacy* and *voice* together.

I feel like, in the end, we were able to *advocate* for Luke and *advocate* for what we know as parents of his potential, and what we felt like what he needed. But I just felt like we spend two hours debating that, and in the end, it was going like, 'Okay, we would give him two hours of speech therapy, and one hour of a reading group a week.' I was like, 'Why did we go through all of that?' (Jennifer, July 1, 2017)

In Robert's discourse, he, too, reveals the perception that he had a *Voice* at IEP meetings with Thomas and Timothy, giving credence to Angie's parallel perception of having *Voice*.

I feel like my input is, is fairly-well received.... But I think overall when I do talk about things; I'm able to articulate them reasonably well. Sometimes [laughs]. But, I think it's well-received, and I didn't think I've ever suggested something when they said no, let's not do that. I mean uh, I think Angie you know, usually backs me up on it. And most of the things that I talk about I think are things that have been talked about in the past, but they seem to have been either removed or glossed over this time. (Robert, personal communication, May 8, 2017)

Dave discusses having a *Voice* in the context of IEP meetings with his daughter, April.

But I did feel [with April] that if we wanted something else added, we could, because usually, the ones I've been in, they have all the documents out. And they read you it line by line. And then, if we have something to add, sometimes they're asking, 'So, is there anything else you want to add?' And if she has something she wants to add to her goals, then they add it in there at that time.... I've always seen they add what we want. And I don't know if that's because of who we are, or because that's normal. (Dave, May 22, 2017)

Diane's discourse reveals that she believes she has a *Voice* when communicating with most teachers: "The teachers, themselves, except a few, I feel like with them I have

a voice, and, like, this is where we are, what do you think?" (Diane, personal communication, July 6, 2017)

Lack of voice. As noted, the discourse of ten participants revealed instances of a Lack of Voice during meetings within the special education process; in other words, school-based team members did not listen to or give credence to a parents' perception, opinion, or request. I present examples of this lack of Voice below.

In this example, Meagan discusses her daughter April, a child with a speech-language impairment. Interestingly, Meagan's perception of *Voice* is different from that of her spouse, Dave, who reveals the perception of *Having a Voice* in his discourse (previous section). In Meagan's discourse, she is discussing the time staff pulled April for services at an IEP meeting. It conflicted with the academic core subject, math. As a result, Meagan was struggling with her math due to missed instruction: "And I thought, maybe we can shift the times she's pulled out. 'Maybe you could shift when you're teaching math.' But none of that was considered whatsoever" (Meagan, personal communication, May 22, 2017).

Danielle, the mother of Peter, who has the classification of Other-Health-Impaired, also revealed a *Lack of Voice* as she discussed her gratitude for the interview. Danielle said, "When I received your number from the other mom she goes, 'Do you want to fill out an opinion?' I am like, oh, yeah. I have opinions. I have 15 years of pentup opinions for my own kids" (Danielle, personal communication, May 25, 2017). Following this remark, Danielle proceeded to list all her issues, concerns, and frustrations with the process, the primary one being that it took an excessive amount of time to get

her son help.

As a third example of a *Lack of Voice*, Diane, mother of Willow, Maddison, Teri, and Sage, ties the *Lack of Follow Through* from the school to a *Lack of Voice*. Diane stated, "So, they hear, and they are appearing when they're there [at the meeting] and [then] the *follow through* is *lacking*. Like, so then, do I really have a *voice or weight*? Because if I have *weight*, then you would do it" (Diane, personal communication, July 6, 2017).

The discourse of Janet, the mother of triplets, reveals an extreme *Lack of Voice*. During the interview, she says, "I felt like I was perceived as making up problems that didn't exist. Because she's a great child, and I feel like it sounded like, am I just complaining, making stuff up, or exaggerating the situation" (Janet, personal communication, May 22, 2017).

Likewise, the discourse of Jennifer, the mother of Luke, a child with a mixed expressive-receptive language disorder, also reveals an extreme *Lack of Voice* through the sarcasm and contempt that team members had for her knowledge and background:

But I just wondered about a parent that doesn't have the background that I have. I just feel like I could see in the same situation, and I'm just being thrown under the bus, or—you know what I'm saying? I did, because they kept referring to, "Mama's real smart," as if that was this big compliment to me. "Mama knows what she's talking about." (Jennifer, personal communication, July 1, 2017)

Chapter Summary

In this chapter, I demonstrated six clear and genuine themes that emerged from the 14 participants in this investigation. First, I provided InVivo11 analysis graphics of

participant reactions regarding the special education process (Figures 37 and 38). My 14 participants are clearly '*frustrated*' with the special education process.

Second, the theme *Power* emerged from the discourse of my 14 participants.

These individuals referred to the *Power of Communication*, both *spoken* and *unspoken*.

They discussed *Procedural Power* and how their *Lack of knowledge*, *Procedural knowledge*, *Experience*, and *Expertise* affected their ability to effectively garner services or advocate effectively for their children with disabilities. Participants also discussed *Power via Personal agendas* and *Authority*, *Power in number*, and *Working Relationship Power*, and importantly how they gained *Power* through *Knowledge* or *Self-education*, which, in turn, *empowered* them.

The third theme to emerge was *Advocacy* from the discourse of my participants. The parents in my investigation discussed advocating for their children both successfully and unsuccessfully, children with disabilities advocating for themselves and instances when they were unsuccessful and marginalized. They also discussed instances where the school or an agency advocated for their children with disabilities and when a school failed to advocate for the needs of the child.

The fourth theme to emerge was *Dignity*. Participants discussed how their children with disabilities gained dignity through employment opportunities, friendships, leadership, recognition, support, and training. However, these participants also discussed losing dignity for themselves and their children with disabilities. Participants felt judged and noted the inappropriate placement of their child. They felt not believed. Parents noted instances of children being outed and hurt by abuse of power. They also discussed

bullying, labels, lack of fidelity in the educational program, exclusion, and the sequelae of the child's impairment.

The fifth theme to emerge was the participants' desire for *Equity* or *Equality* for their children with disabilities. I discussed this theme within a leadership framework, which entails the ethics of justice, critique, care, and the profession. I also provided examples of participants seeking equity and equality for their children with disabilities.

The last major theme to emerge from the discourse of these participants was the theme *Voice*. Participants noted instances when they felt like they had a voice and instances when their voice lacked in the special education process.

In the next Chapter, Chapter VI, I discuss summary participant thoughts. It is a chapter designed specifically for their voice. Each participant describes their summary perception of the special education process and fixes that they would appreciate seeing so that they could more effectively connect with special education professionals who work with their children.

CHAPTER VI

SUMMARY INTERVIEW FINDINGS

Overview

This chapter is composed of participant responses to two summary questions. At the end of each interview, I wanted to get the participants' overall impression of the special education process and what fixes to that process they initiate, if they could. To do this, I first asked all participants to describe their overall feeling of the special education process in one word. I wanted a one-word summary statement that might capture their point of view regarding the process. I then followed up this question with a 'magic-wand' question; that is, what would they do to fix the special education process, if they had the power and could. With this question, I intended to give schools, districts, and state agencies some notice that these magic-wand requests could ameliorate a lot of unnecessary parent anxiety, frustration, and heartache that my participants expressed during these interviews. As such, in this chapter, I present these summary perceptions and solutions (see Table 15). Table 15 provides each participants' one-word reaction and their magic-wand wish(es). Full explanations of their one-word reactions and wishes are provided next.

Summary Parent Perception of Special Education

All participants provided a quick, spontaneous response indicating that this was not a difficult question for them and that they did need to dwell on it. Of the 13 one-word

Table 15

Participant One-Word Summary Perceptions and Desired Fixes of the Special Education Process

Participant	Summary perceptions	Special education process wish(es)
Evelyn	Communicate	Communication
Sandy	Confused	 Communication More frequent, less formal meetings (Check-ins)
Meagan	Confused	Revamp the whole process (a) Freedom for teachers to individualize instruction (b) Accountability (c) Funding—Better personnel
Angie	Follow-Through	Have case managers (a) Be Really Involved (b) Really care (c) Follow-Through (d) Make sure all staff know how to support the child
Robert	Lacking	 Accountability Follow Through / Follow Up
Janet	Lacking	 Reduce amount of time before help arrives More Funding: (a) Support staff, instead of laying them off (b) Provide incentives (c) More staffing—No more kids through the cracks (d) Resources for Training (e) Time for Training (f) Resources for Tools
Carrie	Frustration	More personnel (More warm bodies!)
Dave	Inconsistent	More funding Open-Minded Personnel
Danielle	Disheartened	 Follow-Through Fix testing procedure. Test when requested Better transferability of testing across State lines
Rebecca	Cookie-Cutter	Communication
Joy	Overwhelming	 Communication Funding
Rex	They're doing their best	 Communication Funding Quality personnel (Performance-Based Interviews)
Diane	Effort	 Accountability Follow-Through Funding to support smaller caseloads Funding to support student accommodations Address social needs
Jennifer	Useless	Better/More sensitivity with & when testing & reporting Less contentious meetings

Note. Personal communications (Evelyn, April 7, 2017; Sandy, April 6, 2017, Angie, May 8, 2017; Robert, May 8, 2017; Carrie, May 24, 2017; Meagan, May 22, 2017; Dave, May 22, 2017; Janet, May 22, 2017; Danielle, May 25, 2017; Rebecca, June 7, 2017; Joy, June 24, 2017; Rex, June 24, 2017; Diane, July 6, 2017; Jennifer, July 1, 2017).

summary responses and one slogan, none were positive. It was my impression while conducting these interviews that this summary perceptual feeling was deep-seated, and participants had no difficulty expressing it. Participants also provided logic and reasoning to back their overall perceptions. Where possible, I discuss literature that backs their perceptual claim. See Figure 48 for an illustration of this theme. In Figure 48, the center of the wheel is the theme, the subthemes comprise the first ring, and the participants who



Figure 48. The theme of one-word summary perceptions.

contributed to each subtheme are the outermost ring. As is evident in the illustration, codes, and subthemes for this wheel are the same.

Communicate. To briefly refresh memories, *Evelyn* has a son, Sam, who was in eighth grade at the time of the interview. And for a time, he was a dual-enrolled student having an IEP for speech-language intervention and an IEP for gifted education. When *Evelyn* responded to my one-word question about the special education process, she said, '*Communicate*' (Evelyn, April 7, 2017. As noted in Chapter V, the theme *Communication*—and specifically, the *lack* thereof, or the callous manner that professionals frequently communicated to my participants—is a clear, consistent theme that my participants expressed time and time again in their interviews. Evelyn discussed her response.

IEPs were always an interesting bird. You never knew what they were going to say. In State A, it was hard to get updates on how, you know, throughout the quarters, how the child was doing until the IEP. It was "Okay, well, is he doing better or is he not?" And the Gifted in elementary school only has one hour a week is all they would do. And then, when we moved here, the IEP sends some quarterly end-of-semester or whatever reports, so it was a lot easier to follow along and see that he's advancing in the right direction. With the Gifted-only IEP out here, it was a lot more, "Is he meeting his yearly goals," instead of, "Well, what can I help him at home with." You know, because of Speech especially, you need to have the home help, as well, working on the same phonics or same set as you do in Speech in school and there was no communication with that. (Evelyn, personal communication, April 7, 2017)

In his book, *What works in Schools*, Marzano (2003) discussed parent and community involvement—one of five factors that comprise an effective school. Marzano stated through the work of Antunez (2001) that "One of the defining features of effective parent and community involvement appears to be communication" (pp. 47-48). In his discussion, Marzano reported through work by the National Education Association

(1982) that "Parents have no obligation to communicate with the school. Therefore, it is the responsibility of the school to initiate communication and provide an atmosphere in which parents desire such communication" (p. 48). And while this may sound simple, Marzano noted that effective communication could be confounded by "legal restrictions, district policy" (p.48) as well as the history of the district. Marzano also pointed out through work by Melaragno, Keesling, Lyons, Robbins, and Smith (1981) that the most frequently used school-to-home communication systems remain newsletters, bulletins, and flyers. These, however, are not always effective forms of communication. They make the parent the receiver of information, meaning parents have little opportunity to respond.

Confused. Two of my participants, *Sandy and Meagan*, used the word 'confused' to describe the special education process. Sandy brought up two stories as she explained how these situations were confusing to her. In the first example, Sandy is talking about Chelsea, her 9-year-old daughter, at a younger age, when she was receiving special education services in a preschool setting. Sandy is talking about the classroom teacher's *communication*.

She was very straightforward, and she was like, "I can't have her in my classroom," because it was a Montessori classroom and you need to be more self-driven and able to learn and move on. And she was frustrated with her [Chelsea] all the time, which was a bummer. So as much as she was somewhat helpful, it was like, "Uh, I have to talk to you again." She was always mad and frustrated and just like, "Just take her, I'm done with her." She says, "As much time as you spent on your boys, it's going to take you five times as long to teach this kid." Well, what does that mean? (Sandy personal communication, April 6, 2017)

As I hear Sandy's story, I hear both a *lack of effective communication* and the problem of *Power* as *Repression* (Foucault, 2003), discussed in Chapter II. Sandy reported the teacher's comments toward her and her daughter: "I can't have her in my

classroom," "Just take her," and "I'm done with her." This discourse explicitly disqualifies Chelsea, marginalizing her. Consistent with this *Power as Repression* theme—contained within Sandy's discourse perspective—are subthemes of repressive power. These subthemes include *Power via Authority* (the person in charge of educating Sandy's daughter), *Power via Communication* (explicit communication used to repress and disqualify), *Power via Expertise* (a professional degree held by the special education teacher) and *Power via Personal Agenda* ("my classroom").

In Sandy's second story about the special education process, she discusses her most recent IEP meeting in which the IEP specialist created a moment of confusion for the parents.

At the last one [IEP meeting], this lady started talking, and she didn't make any sense at all, and usually, it's like the one that is typing or overlooking everything, and then you have all your teachers, that kind of talk. And I understand the teachers, I know what they are saying, but this lady, this last time, I don't know why she talked so much, and she talked, and it made no sense. Thank goodness my husband came this time because he was like, "Whatever you're saying, it's going in circles and it doesn't make any sense. Can we continue with the rest of the IEP?" I was like, "I'm so glad you're here." (Sandy, personal communication, April 6, 2017)

I clarified with Sandy whether this individual was the school psychologist? Sandy replied, "No, no. She is the head IEP person" (Sandy, personal communication, April 6, 2017).

I now understood that Sandy was referring to the IEP specialist, an individual who acts as the Lead Educational Authority (LEA) for specialized instruction in each school building. One of the roles of the IEP specialist is to make sure paperwork is in order and all members sign the documents. But they also should know the school and its programs

to aid student program decisions. Sandy continued:

Yeah. And she made no sense this last time. I was like—the last lady never talked. It's kind of like, when you are spoken to, then you talk and this—I don't know. I didn't understand everything because there was that much she was trying to say. (Sandy, personal communication, April 6, 2017)

I asked Sandy to set the scene and describe what the IEP specialist was trying to communicate to her and her husband. Sandy continued:

It had to do with the classroom setting, like how she was saying how disruptive it is to have students coming in and out all the time and how maybe it would be better there was a Special-Ed classroom where the students would stay there. But then, she went on to say we would have her in a regular classroom where she would go off to the side and they would discuss things and I'm thinking, "How is that not disruptive? Now you have a whole other classroom in a classroom where two teachers are talking.

But then it was, 'but we don't know if we can do that because who would be able to tell how the setting is going to be played out until we know how many staff members we are going to have. And once we know how many staff members we are going to have, then we will know how we are going to set up the classrooms and have them be in the Special-Ed setting, the regular classroom, or we are going to pull them out, or have them go to the side.'

And then she said, again, 'we won't know if we have the staff members.' And no one said we have an issue with any of it. We never even said we had an issue. We were just listening, and she just went on and argued with herself amongst being in the classroom or taking her out and how disruptive and again, we won't know until we hire everybody. And we're like, "We heard that three times now." And then my husband was like, "Yeah, can we move on" (Sandy, personal communication, April 6, 2017).

Sandy's discussion and example about her synopsis word 'confused' invoke the discussion above by Marzano about effective communication and its contrast, ineffective communication. She discusses jargon, policy, and procedure that little place in the context that it occurred. To summarize Sandy's second story, then, 'confused' means 'ineffective discourse with a parent,' 'communication lacking clarity,' or 'discursive discourse.' As this discourse took place in the context of a mandated IEP meeting,

Foucault's (2003) *Power as Repression* and subthemes are evident. One noted subtheme was *Power via Authority*; the Lead Educational Authority, a 'gatekeeper,' held all the *Power*. A second subtheme was *Power via Communication*; the meeting contained discursive jargon, policy, and procedure. And a third noted subtheme was *Power via Personal Agenda*; they attempted to *place Chelsea into a program that may or may not have support, rather than individualizing the education program to meet Chelsea's* specific needs.

My second participant to use the word 'confused' was Meagan. As a reminder, Meagan is married to Dave, another participant. They have two children April and Heather who have the classification of Speech-Language Impairment. When Meagan summarized the special education process in one word, she said:

They're very confused. For people who are specially trained in something, they're very confused about how to handle it. They have the processes, but they're confused about *when* they need to use them, *how* they need to use them [emphasis added]. April's Teacher, [Teacher A], is wonderful. She didn't know she had the power to call this meeting that we asked for. In the end, it was [Professional A] who called the committee together, but [Teacher A] had the power to do that. She just didn't know it. (Meagan, personal communication, May 22, 2017)

I then briefly explain to Meagan that she can ask for an IEP meeting as well; that it was not just school members who could call an IEP meeting. I also emphasized she was an equal member of the team. Meagan responded:

And I know that now. With April, I didn't know that. With Heather, I knew it after I researched. I just knew I wasn't letting this go and that's what I've said all along. I said I'm not letting this go. I will homeschool my child because I mean, it's not the ideal situation. It's not what she wants, but I can do it. I'm capable of doing it. And if I needed to, I would, so that she could get the therapy that she needs. (Meagan, personal communication, May 22, 2017)

Hidden within Meagan's discourse are the subtleties of Foucault's (2003) Power

as Repression. The team did not inform my participant about her rights as a parent of a child with a disability. They withheld important information. Hidden in this discourse is *Power via lack of knowledge* and until her second child went through the process, *Power via lack of experience*. Interestingly, *Meagan* acts on this repressive power by doing research. She engages in *Productive Power* (Foucault, 1990) as several of my participants did. *She acquired power via knowledge* which can arguably better allow *Meagan* to advocate for her children at IEP meetings.

Interestingly, Meagan said, "They have the processes, but they're confused about when they need to use them, how they need to use them [emphasis added]" (Meagan, personal communication, May 22, 2017). She brought up an important point as to how processes and outcomes become confused in large organizations. I discuss this confusion in the following section through the voice of my participant, Angie.

Follow-through. Angie, who lives with her husband and two adopted children, Thomas and Timothy, both of whom have disabilities. Thomas, her oldest son, was in ninth grade at the time of the interview and has autism, mental health issues, and behavioral needs. Timothy was in seventh grade. He has academic learning challenges as well as ADHD. Timothy is classified as having a specific learning disability and has been on an IEP since third grade; Thomas, on the other hand, began an IEP in fourth grade.

Angie's one-word summary for the special education process was 'Follow-Through" (Angie, personal communication, May 8, 2017), another clear theme that my participants repeatedly discussed during their interviews. Interestingly, in Angie's explanation about follow-through, she also mentions lack of follow-through concerning

communication between team members, another repeated theme (discussed by Evelyn, above). Angie discussed 'follow through' regarding her son, Timothy. Her story is about the lack of follow-through between and from Timothy's IEP case manager and the general education teacher regarding the accommodations and modifications as written in his IEP.

For Timothy, especially with his memory and organizational issues, we had his IEP I think in March. It was just recently in March or April. One of his general ed. teachers was there. His social studies teacher was there. I am talking about Timothy, and I am saying he has ADHD. He has a bad memory. He has poor organization. He is off task because he is just totally distracted by whatever else is happening. The general ed. teacher is like, "Wow, that is really good information to know. That explains why when I say get your book out, he does not do anything." I am like, "Okay. All of this is in his IEP." I said when we were going through the modifications. I said, "The teachers need to check his agenda." This teacher said, "they write in their agendas every day." I was like, "Have you seen Timothy's agenda? It is pretty much blank for the whole school year." Oh, she said, "That is not good." Yeah? No! Who is checking? I said, "Somebody needs to check and make sure that he is doing that." The case manager said, "Let us put that in the modifications." I said, "It is already in the modifications. You are supposed to be making sure that the General Ed teachers know what modifications they are supposed to be doing." (Angie, personal communication, May 8, 2017)

Angie has recalled an IEP and conversation with Timothy's general education teacher. She supports her son, Timothy, by *advocating* for him. She calls out the lack of follow-through on the part of the general education teacher and the special education teacher, Timothy's case manager. But why should she have to remind professionals of their professional responsibilities? Importantly, here, in the following discourse, Angie highlights where she thinks things are going wrong; she discusses compliance with procedures without consideration of outcomes.

Do you know what I mean? Who is doing that? It is the case manager's job to give the teachers a copy of his modifications and accommodations, and then to

follow up. Has it come to the point where it is all up to me? I must not only check their grades—he was failing a class, and the teacher did not even inform me. It is because it is the parent's responsibility to go on Parent View and check your kids' grades. Okay, that is fair enough. Whatever. Now I have a little reminder on my phone every Monday night to check grades. I would think that if my son is failing a class, somebody is going to shoot me an email and say your kid needs to be coming in at lunch or whatever the case is. I do not feel like there is a lot of communication. I do not think there is a lot of follow through. We write these pretty IEPs, and they all meet those state requirements. Then, who is getting into the meat of it, helping my kid, and supporting my kid during the day? (Angie, personal communication, May 8, 2017)

In this section of discourse, not only does Angie bring up the lack of communication between team members, but she also says, "We write those pretty IEPs, and they all meet those state requirements. Then, who is getting into the meat of it? And supporting my kid during the day [emphasis added] (Angie, personal communication, May 8, 2017). Angie is talking about the focus on 'process' over 'outcome,' a problem that large organizations such as school districts and businesses encounter. In fact, Bezos (2017), in his letter to Amazon shareholders, discussed this problem. Bezos suggests that, as organizations grow, they become too reliant on their standard systems and processes. In his letter, he suggests that while there's nothing wrong with having protocols in place, focusing on processes over outcomes can be dangerous. To Bezos, it is one of the biggest mistakes you can make when running a business. In his letter, he wrote:

A common example is process as proxy. Good process serves you, so you can serve customers. But if you're not watchful, the process can become the thing. This can happen very easily in large organizations. The process becomes the proxy for the result you want. You stop looking at outcomes and just make sure you're doing the process right. Gulp. It's not that rare to hear a junior leader defend a bad outcome with something like, "Well, we followed the process." A more experienced leader will use it as an opportunity to investigate and improve the process. The process is not the thing. It's always worth asking, do we own the process or does the process own us? In a Day 2 company, you might find it's the second. (Bezos, 2017)

Bezos (2017) believes a goal for Amazon is to keep it as a "Day 1" company, where they own the process. In this text, then, Bezos (2017) believes problems are opportunities to improve the current process. Gold, Simon, and Peralta (2013) support this premise. In their Educational White Paper, 'Getting to Outcomes: A User's Guide to a Revised Indicators Framework for Education Organizing' the authors provide an indicators framework to help educational organizations engage in "self-reflection and evaluation of their efforts" (p. 4). At the same time, Gold et al. argue that organizations, funders of organizations, and educators can "use this framework to make a stronger case for an education reform paradigm that starts with and builds the resources and strength of the stakeholders most directly affected by what happens..." (p. 4). In other words, organizations look at the outcomes they need (e.g., student success through follow-through), and build the processes to make that goal achievable.

In Angie's concluding discourse on the topic of follow through, she discusses how Timothy's disability is invisible. With this, she believes, even more, that this is a reason to focus on outcomes rather than meeting the required compliance processes that exist within the structured IEP meeting. She remarks:

This is for especially Timothy who his needs are a little bit more invisible. They are like he does not hand in his homework. Who is at the door of the classroom to say get your homework out? Then stand there and make sure he gets his homework out. You can tell him to go get his homework out. Then he goes, opens his binder, and finds his scissors. Wow, look! Cool scissors! What can I cut? He cannot follow through by himself. That is what his IEP is supposed to be for. Yes, he has a learning disability. He also has this other pretty large issue of organization and memory. Nobody is following through and helping him. We write the IEP. Great! We are done now. Now we just go about our day-to-day business. No. We say in there, 'a teacher signs the agenda,' but nobody has signed his agenda ever all year. What is the point of writing that IEP if nobody is going to *follow through and support* it [emphasis added]? (Angie, personal

communication, May 8, 2017)

Lacking. Robert—the spouse of Angie whose adopted children are Thomas and Timothy (re-introduced in the above section, *Follow-Through*). Robert, however, has a different summary word for the special education process than Angie. He called it, "*Lacking*." (Robert, personal communication, May 8, 2017). Interestingly, he shares this perception of the special education process with another participant, *Janet*, the divorced mother with triplets. However, their definitions of the term, lacking are different. Robert discusses parent education about special education rights and procedures while Janet discusses systemic problems with the process and system. In the following text, Robert replied to my question.

Lacking. I said it at the beginning. I think that my biggest overall thing with the special ed program—and it's not an, an indictment of the people who are running them—but the overall thing is this lack of education for parents on what their rights and responsibilities are, what their kids can get. Especially because we live in the city where so many parents don't speak English. (Robert, personal communication, May 8, 2017)

Here *Robert* bridged two concepts. He refers to the lengthy process for him and his wife to become special education savvy. *Robert* also refers to the Southwest Region of the U.S. in which they live—an area where 47% are Hispanic, and 9.1% are Native American (U.S. Census Bureau, 2015). In this region, effective communication is frequently a cumbersome proposition. In this region, 64.3% of the population are English only speakers, and 35.7% speak languages other than English (U.S. Census Bureau, 2015). Moreover, 29% of the Hispanic children and 34% of the Native American children 5-years of age and older are bilingual. (U.S. Census Bureau, 2015). As Robert is a highereducation educator, he sees the challenges of effectively communicating necessary

information with others who do not necessarily speak the language of instruction. With that in mind, in an urban school district with high rates of immigration, Soutullo, Smith-Bonahue, Sanders-Smith, and Navia (2016) investigated "barriers to facilitating familyschool partnerships with immigrant families." Teachers reported barriers to engagement in 3 broad areas: language and culture, family resources, and families' undocumented status. Many of the teachers in this sample attributed the barriers preventing parental collaboration to school policies (94.4%) and ineffective communication strategies (83.3%). Teachers also viewed the barriers as emanating from the immigrant families, themselves; for example, they reported not attending school functions (88.9%) and were unresponsive to school-initiated communication (72.2%). The teacher participants acknowledge that these families lacked resources for effectively engaging with the schools (88.9%) and that these families were hesitant to engage because of district screening policies (55.6%). At the same time, it is important to note work by Naughton (2004) who reported that family engagement in education mediates risk for children of immigrants.

As noted earlier, Janet also used the word 'lacking' when describing the special education process. Janet's definition of 'lacking,' however, was different from Robert's. Janet began:

Yeah, lacking. I mean, and the actual people that have provided intervention for both Maci and Shawna, I've been pleased with. It's not the actual intervention that I'm having a problem with; it's *accessing* [emphasis added] the intervention. It's not because, and again, one person can do but so much on any given day.

They need the support instead of laying off; they need to have incentives. And sometimes they need to trim the dead wood. Give some of these older teachers' reason to leave. And I know that sounds like, terrible, but some of them, they just, they're like, "Eh, I've seen a million like that." Okay, great, but that one is mine.

And if they educate and mentor the young teachers instead of throwing them in, "Oh, that's your damn problem." "Boy, I'm glad I don't have that class." What? And that's where she got lost all through first grade because one teacher didn't care, and then the other one was too overwhelmed to be able to do anything significant. So, the system failed them, and they failed her. So, lacking. (Janet, personal communication, May 22, 2017)

Janet is talking about a system-wide failure concerning special education. First, Janet sees the problem as a workload issue: one person can do but so much on any given day. Second, Janet sees the problem as a funding issue: they need support instead of laying off and her mention of incentives used to attract and retain teachers. Third, Janet connects her text to a multifactorial issue of teacher motivation, burnout, and even veteran teachers who refuse to change their educational teaching practices (Marzano, 2003; Yilmaz, Altinkurt, Guner, & Sen, 2015): They need the support instead of laying off, they need to have incentives. And sometimes they need to trim the dead wood. Give some of these older teachers' reason to leave. And I know that sounds like, terrible, but some of them, they just, they're like, "Eh, I've seen a million like that." Okay, great, but that one is mine. Last, Janet connects her text to the need for upfront support. She wants adequate training and mentorship for student and first-year teachers (D. M. Hall, Hughes, & Thelk, 2017; Hersh, Stroot, & Snyder, 1993; Wyatt, 1998): And if they educate and mentor the young teachers instead of throwing them in, "Oh, that's your damn problem." "Boy, I'm glad I don't have that class."

Janet's comments above made me reflect on my own first-year experience as a teacher in the schools: Like most teachers, I was young and eager to make a difference. At the same time, however, I felt woefully unprepared for classroom style management techniques; Instructors did not cover this skill in my university coursework for speech-

language pathology. That initial year, my supervision consisted of just two hours of direct supervision. These two hours occurred on my first morning in the school building.

Students were still on summer break. The two hours my clinical supervisor provided were spent showing me the school, meeting the principal together, and introducing me to some paperwork. I longed that entire year for more support. It was a primary reason for my departure from the schools after only two years of teaching. In thinking about this need, the Virginia Department of Education (2016) states that "While not the entire solution, carefully designed mentoring programs can help school divisions recruit new teachers, improve teacher retention rates and help expand the skills and knowledge of the new and veteran teacher." Ingersoll and Strong (2011) and Rideout and Windle (2010) report these same conclusions.

Frustrating. Carrie, the divorced mother of three children whose son Max is in the eleventh grade and has as Other Health Impairment classification, spoke quickly, "Frustrating. Yeah. Frustrating" (Carrie, personal communication, May 24, 2017). I didn't need to ask her to explain; she provided a lengthy story about time, effort, and inadequate support.

My experience was also a little weird because the SLP did a fabulous job and started seeing my child before we had the IEP for eligibility. Because she just felt that strongly about giving him support. Because the year was coming to an end already. So, we didn't have his actual IEP with the Diag. [Diagnostician] until later as the Diag had gone on medical leave. And I didn't get to hear her explain to me the results of her evaluation. The site specialist at that school, because I work at that school, just said here's her report. Do you have any questions? No, okay great. Let's just do the IEP. (Carrie, personal communication, May 24, 2017)

In this section of her discourse, Carrie expresses the frustration of delays and the

frustration of the site specialist [IEP specialist] handing her a report from the school's diagnostician without explanation or discussion. Carrie experiences another form of unproductive Power, *Power via Working Relationships*. Because the two individuals work in the same building, the IEP specialist—the buildings designated Lead Education Authority for Specialized Instruction—circumvented law and policy for convenience. The law and policies explicitly state that parents have the right to participate in meetings. In fact, "public agencies must provide notice consistent with IDEA (2007)" (§300.322(a)(1)). These agencies must also "ensure that parents of children with disabilities can participate in meetings" (§300.501(b)(2) and §300.501 of IDEA). Parents have the right "to participate in, hear out, and be involved in disability decisions that involve the results and interpretation of an evaluation performed on their child" (IDEA §300.306(a)(1)). Teams can hold this meeting in conjunction with the IEP meeting or separately.

So, I never really got her interpretation of what she thought was going on. And they called it a specific learning disability, and because the SLP was working with him, I just said okay. And started researching it for myself at that point. Like what does that mean? (Carrie, personal communication, May 24, 2017)

In this paragraph, Carrie expresses her frustration with not hearing the results. She feels uninformed, and as a result, she becomes marginalized by the fact that she wasn't informed, she doesn't know how to best help her child or even know what is best for her child; she reports having to invest *time* and *effort* into this problem.

The problem Carrie encounters—*Power via a Working* Relationship—is arguably a form of *Power as Repression* (Foucault, 2003). To remind the reader, Foucault, in discussing repression, states that individuals find themselves an object of "exclusion,"

disqualification, exile, rejection, deprivation, refusal, and incomprehension" (Foucault, 2003, p. 44). Concerning this statement, the IEP specialist deprived Carrie of her right to a meeting notice, an Educational Review meeting, information and interpretation about her child's skills, and the ability to ask questions and get answers. Interestingly, Carrie's encounter with this power differential creates the opportunity for a different type of power which she takes advantage of, she begins to find *Power via Knowledge*, a productive power. She reframes the hegemonic discourse that she experiences. She creates a platform for advocacy, a way to argue for the needs of her child. This power has the potential to reach the goal or understanding and thereby lessen or ameliorate the alienation, marginalization, and power inequities that she encountered. She explains:

So as a college-educated parent, that's what you do. You go to Google and say what is this? And you start looking for answers. It's taken me five years to figure out what does that mean and how does that manifest itself in my child? I'm sure that the staff at the school don't have the time or the motivation to do all the research I've done. (Carrie, personal communication, May 24, 2017)

Through her discourse, Carrie identifies the *effort* needed to help son. She also justifies her *effort* with a comparison to the school with whom she now appears to have a *lack of trust*. Her justification is that school professionals in charge of her child have neither the "time or the motivation" (Carrie, personal communication, May 24, 2017) to support her son adequately.

Because obviously, he's not their child. So, why would they? But knowing that I've done all of that is the frustration when I go to the meeting and say this is what I see my child doing. Because I know that I've read everything under the sun I can read about the topic. I've sat there with my son day after day after day doing homework in English and math and science and social studies. (Carrie, personal communication, May 24, 2017)

In the first two sentences of the above text, Carrie continues her criticism of the

school professionals. She expresses a *lack of caring* thereby suggesting that her child is alienated or marginalized. In the remaining portion of the text, Carrie relays her apprehension about all that she's done. It's an expression of 'is it good enough.' That is, 'Is it good enough to overcome the repressive power that I encountered?' This discourse suggests that Carrie continues to feel marginalized despite having gained *Power via Knowledge*.

Writing papers and all the strategies that they give him to help him to do still don't. They still aren't enough. They give him outlines, and the outline is meaningless to him until he gets jump-started on thoughts. And then he can take off from there. But to initiate is just really, hard. And the teachers, they don't have time to be that motivated, that interested, that caring, that committed to helping any student. (Carrie, personal communication, May 24, 2017)

In this section of her discourse, Carrie identifies one of her son's current issues and explains that strategies aren't working. She follows that with the reasons why her son is marginalized and further defines frustration, "teachers, they *don't have the time* to be that *motivated*, that *interested*, that *caring*, that *committed to helping any student* [emphasis added]." Carrie concludes with, "They have 35 kids in their class. They don't have time for that. So, in my mind, the biggest issue is too many kids, not enough adults" (Carrie, personal communication, May 24, 2017). Unfortunately, Carrie justifies her son's marginalization through the *lack of financial resources*. Indicating that it's a money issue, nothing more.

Inconsistent. Briefly, Dave is the computer specialist married to Meagan, another participant. Dave has two children, April and Heather; both of whom have the classification of Speech-Language Impairment. Dave provided the word "Inconsistent" (Dave, personal communication, May 22, 2017). With that, he noted that the special

education process was "inconsistent, especially initially" (Dave). He then continued his thought.

I'd say inconsistent, especially initially. Most parents are just going, oh, I guess I was wrong and move on. Unfortunately, there are not enough people with your experience and background or the lady that we deal with out at the high school. There's a few—[School A] has more excellent people than most. But the education system is lacking that. Because most people got into education not because they're interested, but because they couldn't do anything else, or it was easy, or one summer off, and stuff like that. And there aren't a lot of folks doing it because that's their passion. Yeah, and \$30,000 a year, or \$25,000 a year, you're not going to find people going into it for the passion unless they're going to teach at a college, or stuff like that. (Dave, personal communication, May 22, 2017)

In describing his term, "inconsistent," Dave also provided complaints about his view of the education system in general. However, "inconsistent" primarily relates to his earlier text. Dave knows that levels of training and understanding vary in the education system. He also knows that one may get an individual who cares about a child and has deep background knowledge and skill, and then again, one may get the opposite. When a professionals evaluated his daughter for services, Dave had this experience. One professional provided a cursory screening. Moreover, this professional wasn't sure how to pronounce the child's name. When this professional met with the parents, she not only repeated said the child's name incorrectly but also informed the parents that their child was normal. Another professional, however, took the time and completed a thorough assessment, finding that their child did indeed have a moderately significant disability. As such. Dave's 'inconsistent' refers to differentials in training and specialization that impact educational outcomes, a differential in caring that affected the parents' level of trust, and a differential in communication that made the parents feel alienated and marginalized their daughter.

Disheartening. "Disheartening" is Danielle's word (Danielle, personal communication, May 25, 2017). Danielle has three children and lives on a base in the Southwestern U.S.; she helps other mothers on the base cope. Her son Peter has the classification of Other Health Impaired. Danielle's explained 'disheartening.'

It's disheartening. It really is. It becomes a case of, do you think you can facilitate it at home and overcome the things that are lacking in the public school. If you think so, where do you want to put your energy? Fulfilling it at home and making sure your kids are getting it at home now, or still staying and fight. Yeah. (Danielle, personal communication, May 25, 2017)

Danielle is expressing the frustration surrounding the length of time it took for one of her children to be tested and receive support. She describes the energy involved in providing specialized instruction at home versus the energy involved in fighting for the needs of the child within the school system. She describes the length of time it took for a friend of hers to get reading support for a child with dyslexia and dysgraphia, which took longer than her child. Danielle expresses the marginalization that she feels through efforts required to obtain support for her child due, in part, to resource scarcity.

Cookie-Cutter. Rebecca, the married mother of two children and employed full time with a professional degree, has a son, Garrett, who is currently eleven and in seventh grade. Garrett is dual enrolled and has learning disabilities which are not being addressed by the large metropolitan district in the Southwestern U.S. despite repeated requests for support. Rebecca's one-word summary response is "Cookie cutter" (Rebecca, personal communication, June 7, 2017). She follows with an explanation as to what this means:

It would be cookie-cutter. They had strengths that I understood through testing, but I didn't feel like they had a full picture of my child. Look, the IEP, it just didn't, it felt more like it was a cookie cutter IEP that Garrett was put into rather than as an individualized education plan for him. (Rebecca, personal

communication, June 7, 2017).

A little further into the interview, Rebecca revisits what she means by 'cookie-cutter:'

Yeah. It was, I mean everything was all prepared. And they said, we've got it all ready, we'll just breeze through it. You can sign. We should be out of here within the hour. And sure enough, everything was in there. It was goals that you would expect to see straight out of a textbook. It was...nothing was specific to Garrett. (*Rebecca*, personal communication, 2017)

Rebecca, thus, describes the lack of the 'Individual' in the 'Individual Education Plan,' a plan that, by law, is tailored to the student strengths and needs. This lack of individualization is a denial of FAPE for children with disabilities and a method of silencing their unheard voice by creating an academic program where academic progress is likely to be *de minimis*; that is, too trivial or minor to merit consideration. With that in mind, on March of 2017, the Supreme Court ruled on 'adequate yearly progress' of IDEA (2007) after hearing *Endrew F. v. Douglas County School District* (2017). Walsh (2017) wrote that the Supreme Court ruled "unanimously that schools must do more than provide a "merely more than *de minimis* [emphasis added] education program to a student with a disability (p. 1)." Walsh (2017) discussed the ruling of Chief Justice John Roberts and quotes Roberts' (2017) summary statement.

When all is said and done, a student offered an educational program providing "merely more than *de minimis*" progress from year to year can hardly be said to have been offered an education at all. For children with disabilities, receiving instruction that aims so low would be tantamount to "sitting idly…awaiting the time when they were old enough to 'drop out.' (p. 14)

Walsh (2017, p. 1) also notes that Roberts (2017) said, "The IDEA demands more. It requires an educational program reasonably calculated to enable a child to make

progress appropriate in light of the child's circumstances (pp. 14-15)." (Thus, the cookie-cutter goals developed for the *individual needs* of Garrett create the potential for a *de minimis* education.)

Overwhelming. Joy, married to Rex, another participant, has two children. Their daughter Sierra has a significant language disorder. She responded to the 'one-word description' with "Maybe *Overwhelming*. To me, I would say overwhelming. Because you can't just walk in and say, 'Hey'" (Joy, personal communication, June 24, 2017).

Joy's story about her daughter Sierra had been one of *effort* and continual need for *advocacy*. In her discourse, she recognizes that her daughter's issues are significant, and she recognizes the limitations of the school system, but at the same time she wants the school to help and for those in the school to understand her daughter's needs.

Yeah, and Sierra is severe. It's hard to expect the school to be able to do everything that Sierra needs. The older she got, the harder it got for everyone around her to help or to understand or to be involved. When it's kindergarten, first grade, it's a little easier to understand but then second grade it was hard. (Joy, personal communication, June 24, 2017)

Joy was seeking support from the school, advocating for her child, however, as she explained, the district threatened to pull special education support if she and her husband did not accept the disability category, autism.

They told us that we would lose support completely if we didn't go along with it. That we would not get, at that point, Sierra had a teacher's [aide], a paraprofessional. And she got accommodations for testing, like all that. That we would lose everything. It didn't feel right, so I started researching it and then we had probably four or five meetings. (Joy, personal communication, June 24, 2017)

Joy's discourse reveals *Power via authority* and *Power via Personal Agenda*. It is my view that Joy's expressed feeling, "overwhelming" is one that is tempered by the

nature of an interview, even with the use of pseudonyms and anonymity. Joy's eyes welled up several times during the interview when she recalled and explained these past events. Sierra's right to a FAPE, via her support services, were held over the parent's heads in the form of blackmail: a case of, 'Do it our way, or else.' Joy expressed how she tried advocating for her daughter, *Sierra*, but the district wouldn't listen; they had *their own agenda*: "Yeah. I mean they were never rude or never shut us down exactly, but it was like a voice without a voice. Like they'd listen, but nothing changed" (Joy, personal communication, June 24, 2017).

Joy expresses the voice of the marginalized. She is *a voice without a voice*, a form of *alienation*. And she reiterates why she felt overwhelmed when revisiting this issue in her text. *Joy* restates this instance of *Power via Authority* and *Power via Personal Agenda* as the district's director of special education pressed for the autism label. *Joy* said, ".... we don't understand, but they wanted an autism diagnosis, and there was nothing else that they wanted to do but that diagnosis" (Joy, personal communication, June 24, 2017).

They're doing their best. Rex, the spouse of Joy, responded to the 'one-word description' question with, "Can we do a slogan? (Rex, personal communication, June 24, 2017)." His slogan: "They're doing their best." He added, "They're doing their best, but if they're reading the wrong book if they're using the wrong information, the best isn't enough" (Rex).

Rex was expressing his frustration with Sierra's situation as he had indicated earlier.

So, the IEP was well established that speech was our focus and they did everything but speech. In her IEP, we tried to emphasize more speech-language intervention. But in the end the speech-language pathologist, there was, there was just kind of a wave where there wasn't a good speech-language pathologist, then there was a qualified one. However, she had a different take on what we should do for Sierra, so there was never really like a good intervention in the speech-language pathology area. (Rex, personal communication, June 24, 2017)

In sum, "they're doing their best," means that while the team wrote the IEP for Sierra's language needs, there was a lack of follow-through on this plan due to staffing/support challenges. For Rex, a FAPE (U.S. Department of Education, Office for Civil Rights, 2010) was unavailable for his daughter due to staff turnover and not tailoring services to Sierra's needs. Rex had given examples in the interview about his daughter's happy and sad "eeeee" noises:

It was less about her education and development and more about like—getting her to behave, on stopping them [the 'eeees'] without replacing them. And we felt like if we went along with what their path, that we would *damage* [emphasis added] our daughter. (Rex, personal communication, June 24, 2017)

Rex expresses through his discourse that his daughter would *lose dignity* by not being allowed to be herself. He considers removing her "eeees" without replacing them with something else *inappropriate methodology/pedagogy*.

Effort. Diane, the mother of four children with disabilities, replied quickly to this question. She remarked, "*Effort*" (Diane, personal communication, July 6, 2017). And then, she explained:

We get out of the special education process whatever it is that I'm willing to work hard enough to chase down. Point blank, like Maddison, has a really hard time getting stuff down on paper out of her brain. That processing is tricky. Thank you, *Siri*, that got better. And now, anything she writes, she talks into her phone and Google docs, it writes it for her. But I did massive work to get her approval for tech. Well, they said she was not approved for tech, but if I bought the tech, they would load the software on it. Because she didn't qualify, so we bought her a

smoking computer so that it could have IQ word and text to speech.

Text to speech and that kind of stuff, before Siri. And then I taught her how to use it. So, that's what I mean by effort, *it's me* [Emphasis added]. Like so if we didn't buy the technology, she wouldn't have had that. If we didn't buy the smartpen, she wouldn't have had that. So, the evaluations are helpful for me because then I can go to research and find what to do and try and help to beat the curve so that we have a tool to help us to be productive. (Diane, personal communication, July 6, 2017)

In other words, through Diane's one-word response, "effort," she expresses, it's me. It's me that is helping Maddison achieve equality through becoming independent (using Siri, text-to-speech, smart pens). It's me that is helping Maddison gain dignity through support at home, a parent-child effort. It's me that is fighting the fact that she may lose dignity and lose the goal of equality with peers by not having access to these technologies. It's me means sacrifice, the financial burden of purchasing all this technology without support from the school. It's me means there is a difference between parent and school expectations.

Useless. Jennifer, the mother of four children, has a son, Luke, age 14, who has the classification of speech-language impairment, specifically a mixed expressive-receptive language disorder. When I asked Jennifer for her one-word description, she apologized for her comment through a couched phrase, "It sounds terrible, but 'useless'" (Jennifer, personal communication, July 1, 2017). She then explained:

When it comes to the school and early intervention, and what not, I just felt like it was a waste of time. I felt like it was a lot of stress and frustration, and—even if I'll give credit to the administration of his current school, that they were very cool with us as far as this. But I just felt like, overall, for all the effort, and all the stress, and for all the trying to figure it all out, I felt in the end, it didn't really lead to an improved situation for our son. (Jennifer, personal communication, July 1, 2017)

I explained to Jennifer that I found this interesting and that her statement aligned

with the responses to her survey in which she had indicated that she didn't see the special education program helping her son in the school, home, or community. And I noted that that perception was discouraging. Jennifer chucked at this statement of mine: "[Chuckles] Yeah, and it could just be because of what he has is not—autism is something that's widely known, and there are a lot of services for it" (Jennifer, July 1, 2017).

I then talked about language services for children with autism versus children with a language disorder, how similar the services are, and how I might approach the situation as a professional, having had seventeen years of school-based experience in working with children with varying levels of autism and language difficulty. She indicated her agreement and then expressed more about why she thought Luke's special education program was "useless."

And that's where I'm at, too. And there was once where the therapist at the school, he just did not want to participate at all. And there just wasn't anything that was also very motivating and interesting. Like you've got to know a kid's interests, and like if you hand him this little game with owls and stuff—he doesn't care about that [chuckles]. And he doesn't understand why he has to sit in this room with you with this black and white printout with owls on it, and why he's not in his classroom using these awesome Montessori materials and doing all these cool things with their math cubes, or whatever. He had a bunch of girls that loved him. They were just super protective of him. And he loved spending time with them. I don't blame him for not—but as I said, I couldn't see—I'm just trying to figure out what we want to do at this point—because he is, on his own, really progressing, and the structure that's at the school is part of that. It's not special ed., it's just the school itself. (Jennifer, July 1, 2017)

In Jennifer's discourse, 'useless' means a Speech-Language Pathologist who hasn't taken the *time* to get to know her child. It also means a therapist who provided her 14-year-old child with *inappropriate* cookbook therapy activities such as worksheets on "purse-dogs" or board game with owls designed for children 10 and younger. And useless

means, that the therapy services *separate* her child from supportive peers. To Jennifer then, 'useless' means 'losing dignity' through (1) unsupportive staff, (2) inappropriate placement, (3) inappropriate methodology/pedagogy, and (4) through separation from peers. This discourse also invokes Foucault's (2003) Power as Repression; her 14-year-old marginalized by becoming an object of exclusion and exile as (being separated from peers), as well as an object of rejection and incomprehension (providing cookbook therapy to a child that the therapist does not know how to help).

One-Word Perception Summary

The 14 summary statements made by the participants of this investigation include the following, *communicate*, *confused*, *follow-through*, *lacking*, *frustrating*, *disheartening*, *cookie-cutter*, *overwhelming*, *'They're doing their best*, *'effort*, and *useless* and the explanations behind them directly connect to the research questions of this investigation. To revisit them briefly, the focus of this research project surrounds parent perceptions of the special education framework. I asked a multi-part question which was designed to look at the discourse that parents of children with disabilities experience. I have intended to answer what was the function of the discourses these parents experienced, how the discourse functions as it acts on these parents, and to explain why the discourse functions in that uncovered way. As I based this project on grounded theory, I am also interested in uncovering any alternative explanations that the data might present. Critical moments of the special education framework challenged my 14 parents. These experiences solidified into summary perceptions of that process.

Evelyn's need is effective communication. Her need is one of five factors that

comprise an effective school (Marzano, 2003). And following Marzano's explanation of communication, this is easier said than done; but as Marzano stated it is the district's responsibility to initiate the communication as parents are under no obligation to do so (p. 48).

Sandy and Meagan, who described the special education process as 'confused' consider the discourse within the special education process to be repressive. *Power* as Repression (Foucault, 2003) factors load these stories. In Sandy's discourse, there was both a lack of effective communication (see Marzano, 2003) and the problem of Power as Repression (Foucault, 2003). 'Confused,' to Sandy meant 'ineffective discourse with a parent,' 'communication lacking clarity,' or 'discursive discourse.' Several factors contributed to Sandy's discourse concerning repression. First, she experienced Power via Authority; there was an LEA, a 'gatekeeper,' and the special education teacher, the individual in charge of educating Sandy's daughter). Next, Sandy experienced Power via Communication; there was explicit communication used to repress and disqualify as well as discursive jargon, policy, and procedure. Third, Sandy revealed *Power via Expertise*; the special education teacher holds a professional degree. And last, she encountered Power via Personal Agenda; the special education teacher who described the learning environment as "my classroom" and who attempted to place Chelsea into a program that may or may not have support, rather than individualizing the education to meet Chelsea's specific needs. Within Meagan's discourse that revealed *Power as Repression* (Foucault, 2003), the team withheld important information. She experienced the repression from the factors Power via lack of knowledge and until her second child went through the process,

Power via lack of experience. Meagan acted on this repressive power by doing research. She engaged in *Productive Power* (Foucault, 1990) as several of my participants did. *She acquired power via knowledge* which can arguably better allow Meagan to advocate for her children at IEP meetings. Last, Meagan's discourse revealed a challenge of large organizations, the confusion that can occur between processes and outcomes.

Angie's need is follow through. In her discourse, she revealed the lack of communication between team members, but she also brings up an issue that organizations can experience when they focus on processes rather than outcomes. Bezos (2017) and Gold et al. (2013) discuss this problem that *Angie* experienced and suggest that organizations look at the outcomes they need (e.g., student success through follow-through), and build the processes to make that goal achievable. Angie believes that focusing on outcomes rather than processes is critical for children like her son, Timothy, whose disability is invisible.

Robert and Janet described the special education process to be 'lacking.' In his discourse, Robert revealed the length of time it took for him and his wife to become Special Education savvy. He also revealed his concerns for minority populations in his State who may be dealing with the special education process and acknowledged the challenges of effectively communicating necessary information with others who do not necessarily speak the language of instruction. Janet, on the other hand, discussed a system-wide failure. She saw the problem as a workload issue, a funding issue, the multifactorial problem of teacher motivation, burnout, and veteran teachers who refuse to change their educational teaching practices, and she connected her discourse to the need

for upfront support—adequate training and mentorship for student and first-year teachers.

Carrie is frustrated. Carrie expresses the frustration of delays and the frustration of the site specialist [IEP specialist] handing her a report from the school's diagnostician without explanation or discussion. She experiences a form of repressive power due to her working relationship. She expresses frustration at not hearing the results; being uninformed, she feels marginalized. Carrie also tries to overcome this marginalization by investing considerable time and effort into her child's problem, gaining power through knowledge. She also explained that the marginalization comes in part from limitations imposed on the teacher. That is, "they don't have the time to be that motivated, that interested, that caring, that committed to helping any student [emphasis added]" (Carrie, personal communication, May 24, 2017). In her story, Carrie works at reframing the hegemonic discourse and replaces it with an advocacy platform. This power has the potential to reach the goal or understanding and thereby lessen or ameliorate the alienation, marginalization, and power inequities that she encountered. In my view, Carrie's story is disheartening, as, in the end, she justifies the district's marginalization of her by indicating it results from the *lack of financial resources*, a money issue, nothing more.

Dave considers the special education process to be *inconsistent*. He experienced Power differentials via *Communication* and *Caring*. He also experienced the effect of *inadequate training*. His text expressed the frustration of seeing his daughter alienated and marginalized.

The special education process disheartens Danielle. She experienced a Power

on, district policy was to put her child into a placeholder and act on the request only when the time came. Delay made Danielle feel disheartened. The required effort marginalized her. It took *effort* to support her child at home and to obtain support within the school system. A compounding factor in Danielle's case was resource scarcity, a lack of qualified personnel to carry the testing forward.

Rebecca wonders what happened to the Individual in the Individual Education

Plan. She views the process as cookie-cutter. Her son, Garrett, suffered due to lack of an individualization education plan; FAPE was elusive as anyone could have had his goals.

A denial of FAPE is a clear method of suppressing and silencing those who cannot speak for themselves; it also creates the clear potential for a *de minimis* education.

Rex ('They're Doing Their Best') and Joy ('Overwhelming') experienced discourse that served to disempower. They experienced Power via Authority and Power via Personal Agenda. Joy felt marginalized by the district's efforts; as she stated, she was "a voice without a voice." The experience, context, and discourse served to alienate her perspective.

Diane's view of the special education process is that of personal effort. She discussed a clear difference in *expectations*, family vs. that of the school. Diane's text revealed how she felt *alienated* by the school. In Diane's eyes, Maddison was succeeding only because of the home support; the family had to sacrifice to support Maddison; she reported feeling the need to do this so that her daughter would not *lose dignity* with her peers and be successful. She was seeking *Equity* and *Equality* for her child, and the

school was not supporting this effort. As such, the family gave Maddison her entitled FAPE via home support.

Jennifer considers the special education process 'useless.' She discussed how her son was *losing dignity* by receiving special education support. Her text described an unsupportive staff, inappropriate placement, inappropriate service methodology/ pedagogy, and separation from peers.

Magic Wand

Following my summary perceptions question, I followed up with a 'magic-wand' question; that is, I asked participants what they would do to fix one or two things about the special education process if they had the power and could. With this question, I intended to give schools, districts, and state agencies some notice that these magic-wand requests could ameliorate a lot of parent anxiety, frustration, and heartache that the discourse within this dissertation demonstrates. The Magic-Wand results are illustrated in Figure 49 and followed by a description of the results.

For this theme, *Participant Special Education Process Wishes*, the Subthemes, or branches of the theme, are *Funding, Communication*, a desire to *Fix Procedures*, the act of *Caring, Follow-Through, Accountability*, and *Special-Education Processes*. The codes, or limbs that contribute to the subthemes, however, are now the participants of this investigation. What they discussed, how the participants wish the special education process to change, are the individual leaves, or factors that comprise a code.

Accountability. Robert, Meagan, Danielle, and Diane wished for better *Accountability*. During Robert's interview, he said to me, "Accountability so that we as

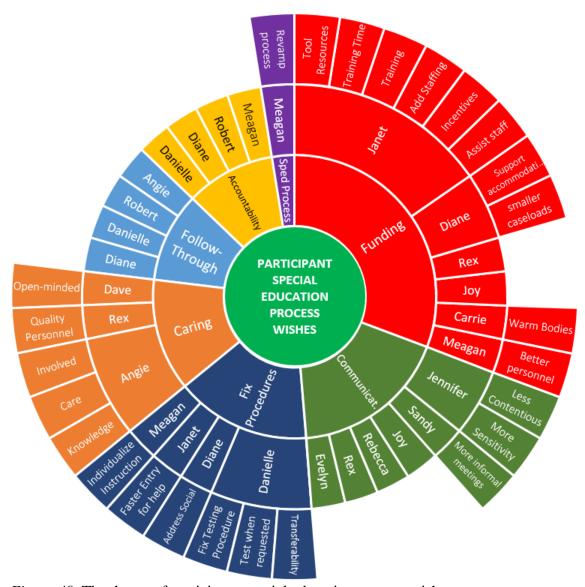


Figure 49. The theme of participant special education process wishes.

parents had a, a way of knowing. It's like you know, 'Hey, if you can...' Don't promise us this is what's going to happen and then don't follow through on that." (Robert, personal communication, May 8, 2017).

As a second example of Accountability, and while Meagan wants to "Revamp the

whole process," (Meagan, personal communication, May 22, 2017), her discourse specifically focused on *Accountability*. She addresses those who are in power and make decisions, saying, "I hate to say this. It sounds awful, but they need quality people in the positions of making decisions. The letter that I received from [Administrator A in District A], I believe it is, was a copy and paste nightmare. That should never have left her office. That was somebody who was just slapping words on a paper hoping that I would go, oh, it's official" (Meagan).

As a third example of Accountability, Danielle brought up that her child had to wait in line to get tested. She would prefer that teachers be "allowed the freedom to go, 'This kid needs to be allowed to do this; needs to be able to slow down or needs to be able to speed up.' If they cannot give that test there is a way—there has got to be. I do not know what it is, but there has got to be a way to let teachers teach and still be held accountable" (Danielle, personal communication, May 25, 2017). In other words, Danielle seeks the freedom for teachers to make decisions about children so that those that need help can get it right away and those that need challenges can have the same. She wishes for this and to hold teachers accountable for their actions at the same time.

And last, Diane, the mother of four children with disabilities, discussed her wish for accountability in this manner.

I quite frankly, I would love to go collect information, be able to walk away from them and be able to come back with the goals and make them assign it so that the whims of whatever don't drive it but what, really makes them support success. You know, I would have loved to have written the goal about that there is somebody with her so that we didn't ever have to get to suicidal. They don't live that; they don't see it, they don't know. I would love to be that person that wrote that goal. And then, get them to sign it that best they support it. And then, quarterly follow up how those goals are going. Once a year is a crap shoot

because if it takes two weeks to go from A's to F's or I should have an update all the time without pestering someone. (Diane, personal communication, July 6, 2017)

At a different point in her interview, we discussed goals and whether staff informed her about progress on those goals. In that discourse, Diane reiterated her wish.

If I go in, especially with the SLT [Speech-Language Technician], when I go in, there is no progress report [available] to hand to me. And that's the difference. If I go into *Sage*'s in the elementary school, okay here's our progress we were like at 52, and now we are at 64, we are so excited. And we got this, and this and these are not here yet, so we are not addressing them. I know exactly where she is at and what she is doing and what I should be working on. They can also tell me that in-between those progress reports. And so, parent-teacher for *Teri* at [School A]—she is an awesome SLP—couldn't get that at [School B] but we get it at [School A]. So, a whole bunch of it is the SLP and how well they track their data and run their reports and how their system is streamlined to better handle insanely large caseloads. I get it. I have never been handed a progress report on anything for *Maddison* since we went to high school. So, then we don't know. But anyway, I'd like to write goals and have them sign it and report to me. That would be groovy. (Diane, personal communication, July 6, 2017)

Additional Personnel. Carrie would like additional personnel. Carrie stated in

her discourse:

They have 35 kids in their class. They don't have time for that. So, in my mind, the biggest issue is too many kids, not enough adults.

More adults helping the kids. I think if they, honestly, I've said this out loud numerous times in the last couple of months as they talk about the budget issue. If we could lose a couple of administrators and hire 25 EA's, everybody would be better off. We just need more adults helping in the classroom.

You can't have 35 kids in a class and expect anybody who has any kind of issue to do well. Your gifted kids will figure it out. They'll probably do just fine in life. And yes, they need to be challenged. But it's the special ed kids that aren't going to make it without that adult being there to help them through the process.

So, it just takes somebody with time and a big heart and interest enough to figure out what the problem is and help the student work through it. Whatever their issues are. Not just my kid, but all the kids that I work with also could just use more warm bodies. More warm bodies in the classroom helping them get through (Carrie, personal communication, May 24, 2017).

Time. Janet put it bluntly when discussing her magic-wand wish, saying, "One thing is it wouldn't take so damn long" (Janet, personal communication, May 22, 2017). Janet was referring to the considerable amount time it took before her child began receiving specialized instruction. She added: "I don't feel it should have taken two and a half years to get a diagnosis before we have just written an IEP last week" (Janet).

Communication. Six of my participants brought up communication when discussing their magic wand wish, but it was Rebecca who discussed her wish for communication at length:

Okay. Communication. I just, I reach out to the teachers, and they were great about getting back to me. But not great about knowing what was going on. So, they didn't know what was happening, or what should be happening, but sometimes both.

And then getting in touch with somebody who knew what was happening was awful. It was just awful. And then the way they communicated to me. So, just, if I could wave my magic wand, I've thought a lot about this in the last day, 24 hours. And its communication over and over and over. How you communicate, when you communicate and who communicates.

I would like to be able to, if I could go back, I'd like to talk to the person who is going to be sitting with my child for three hours over two days, or one day, or however long it took them. I don't even know. I don't even know, nobody told me. I would like to know exactly how it's going to happen. And when I did ask that question, and I was told, well, we can't give you those answers because then you could prep him. It's like; I don't want to know what's on the test, I want to know is it going to be in his classroom? Is it going to be in the closet? Are you comfortable with children? Have you done this for many years? I think we must be writing. Should I send him with a pencil? I just didn't have any answers. There was no communication. (Rebecca, personal communication, June 7, 2017)

Joy and Rex demonstrated that they were on the same wavelength when it came to the special education process, they both said, "*Communication*" in unison (Joy and Rex, personal communication, June 24, 2017).

Evelyn also replied with *Communication*. Evelyn used the same theme when she

defined the special education process in one-word. Her explanation of that one-word summary was about the lack of communication.

More communication, better communication. Because sometimes it would go through him and his sloppy old backpack, come home and—last year, I didn't have a single report, and I was like, "Wasn't I supposed to get those throughout the year, you know, for the Gifted?" And all four were in his sloppy backpack that he never gave Mom.

So yes, it would be nice to send even just a quick, "Hey, reports came home today." Because even at this age, they tend to be very lackadaisical on giving forms to Mom and Dad, so it gets to be pretty hard sometimes knowing is it the kid not communicating by not handing it to you? Is it the teachers not communicating? Is it the, you know, the counselors or the teachers or who is it that's not communicating well? (Evelyn, personal communication, April 7, 2017).

The last participant to use express communication was Sandy. She replied to the magic wand question with some simplicity: "Like, more communication" (Sandy, personal communication, April 6, 2017).

Formality. Sandy also wanted more frequent, less formal meetings. She called them "check-ins" (Sandy, personal communication, April 6, 2017). In my view, more frequent, less formal meetings create an avenue for *communication* and become the avenue for *accountability* and *follow-through* and a platform for case managers to have increased *sensitivity*, to become *open-minded*, *involved* and *care*. This fix would thereby eliminate many concerns (see Table 15) reported by my participants. In Chapter VII, I discuss a model solution for school districts to consider regarding these issues known as the 3-to-1 Model of Intervention. As a speech-language pathologist, I have seen and implemented this model with considerable success, using it for 14 of my 17 years in the public schools. Importantly, the model does not increase costs for a district who choose to implement or run the program. Moreover, there is field, pilot, and district data on the

model's success. The model has been adopted by large metropolitan and small rural districts in the Pacific Northwest and Intermountain region. I discussed the model with several participants; they were all open and receptive to such a change.

Increased funding and resources. Half of my participants discussed this theme. As noted in Table 15, Dave has the simple wish of more funding without specifics. Carrie and Janet wish for more personnel, while Joy, Rex, and Meagan specifically requested quality personnel. Diane wishes for funding that would promote smaller caseloads and student accommodation needs. And Janet also asks for funding that would support staff (i.e., incentives, instead of laying them off), funding resources for training, funding resources for the time it takes to train, and funding for the tools needed to support supports. Below, I provide comments from three participants regarding funding:

Joy replied, "Funding, an obvious one. Like if there was more money, obviously, I think everyone would be.... you know, what I mean, if there were more people and more staffing" (Joy, personal communication, June 24, 2017).

Carrie stated a similar sentiment to Joy. She said:

More adults helping the kids. I think if they, honestly, I've said this out loud numerous times in the last couple of months as they talk about the budget issue. If we could lose a couple of administrators and hire 25 EA's, everybody would be better off. We just need more adults helping in the classroom. (Carrie, personal communication, May 24, 2017)

Janet, however, explained her funding concerns in detail.

That the state would have the resources to have the intervention. Because the absolute last place this state or any state, or our country can afford not to invest, is education.

And especially when people have special needs. Those are your at-risk people. Those people are at-risk for underperforming, underemployment, poor decisions, drugs, alcohol, promiscuity. Like, that is a high-risk population because they learn

that they just can't do anything.

They can't do anything right, so why bother and try? And they need people who know how to help them with those obstacles so that these people can function at their optimal levels. Because I see people fall through the cracks, and that's where I'm like, well, I'll be damned if she's going to fall through these cracks. I will just keep on, and keep on, and keep on.

Because that's what I saw that was going to happen. And if I had to, I would have been paying for outside intervention. I'm a single mother of triplets. And I am on disability for medical issues. I don't have a lot of extra money. But I bet you; I'll tell what, I will figure out how to do this because it is just that important. So, I think they are so poorly resourced for staffing. (Janet, personal communication, May 22, 2017).

Fix procedures. Besides the wish for Follow-Through, discussed above, Danielle also wished that some procedures be changed, including the procedure for initiating testing and the wish for better transferability of testing across State lines. Danielle discussed these issues in her Magic Wand response.

For the district, not make it, so all first graders test at this time, fifth graders test at this time, seventh graders test because that stopped us. That stopped [my son] in his tracks, and he was told he would not test until it was time for first graders. Let people test when the parent requests, as soon as the parent requests. I know it cannot be immediate, and I say that, but I have a hard time believing that. (Danielle, personal communication, May 25, 2017)

Danielle and I went onto other interview questions, but Danielle returned to my 'magic-wand' question on her own with another procedural concern that she wished was fixed.

You asked earlier about a magic wand. I wish there were a way to make these evaluations better understood across state lines. My kids are not the only military kids on the planet, and there is a lot of military kids on IEPs all the way from one end of the spectrum to the other. I have watched friends have their kids get IEPs dropped, or misunderstood, or not validated numerous times. Again, both ends of the spectrum. It is more common than not. Yeah. I could think—one, two, three, four. Half a dozen kids at the drop of a hat that I can say, that mom had to fight tooth and nail for somebody to recognize that this actual doctor's diagnosis says it. As I said, some of those kids are visibly [disabled]. You can see, oh, that kid

has needs. Then some of them do not. Even the ones that are physically manifesting their needs, sometimes they get dropped. I wish there were a way across the board. That is the magic wand. (Danielle, personal communication, May 25, 2017)

Personnel qualities. Dave, Jennifer, and Angie spoke of personnel qualities. As indicated by their discourse, these wished-for qualities are a direct result of their special education process experiences.

After mentioning 'funding,' Dave stated: "I think it makes the frontline people a little more open-minded." (Dave, personal communication, May 22, 2017)

I asked Dave to dig into his 'open-minded' comment a little deeper and explain what he meant by that. Dave replied:

They weren't listening to the parents for one. They weren't listening to the teacher, so they were just not opening their mind to what was being said about the kid.

You extrapolate that to the parents who don't have time to deal with their kids and stuff. And what's being missed? Just because a kid's not doing well. We had a friend, this kid, they had him on grade-level, and he was a troublemaker. They were saying he was horrible. Well, it turned out this kid was probably the smartest kid that ever went to [School A]. (Dave, personal communication, May 22, 2017)

Jennifer replied quickly to my one-word summary question with '*Useless*' (Jennifer, personal communication, July 1, 2017), so I was intrigued to discover what her Magic Wand wish might be. Jennifer provides discourse related to *Sensitivity* and *Power*.

Just some sensitivity when it came to the actual testing, a desire that those [assessments] were done under optimal conditions, and just a recognition that, "Okay, we did these tests, but halfway through, he refused to continue," and not over-interpreting the results of that test knowing that he was not happy, or really even engaged during the testing process. And like I said, I get that that's probably going to be hard. They're trying to get probably a lot of kids tested, and so it's like, "Okay. We've got to do it now; this is our window of time." But I would have liked—I would have been more receptive to the results myself if I had known that he had done it under conditions that he wasn't stressed or unhappy, and that he was actually engaged. Because a lot of it was, he just didn't even—

And I have another friend who has a son with pretty severe special needs, and she's like, "You just have to fight for them. You just have to advocate for them." But I feel like there's just this disconnect between the people that are offering the services, or the people that are doing the testing, and the parents. Or between the teacher and the parents, that they're just automatically dismissing the parents that think the testing didn't go well, or just making assumptions about the parents. That we're somehow in Lila-Land or somehow in denial, or if we push hard for something, that, "Oh, we're that kind of parent all of sudden." And my question to that is, "So you just want parents to just roll over and let you do whatever they want because it's easier for you to just put a plan in place, and not have to get parents' approval?" So, I just wish there could be a way for that to be a lot less—I mean, "combative" isn't the right word—but less contentious. Because it just seems like they love you if you just basically submit to everything they say, and just say, "Okay, I trust you. I'll put this in your hands." But then, all of a sudden you get that, "Oh, great. These kinds of parents are going to be the ones that are going to be calling us all the time, or whatever." And certainly, there probably are irritating parents out there, I'm sure. But I just wish that parent can be taken more seriously in the whole process (*Jennifer*, personal communication, July 1, 2017).

Last, to the Magic Wand question, Angie replied, "I would magically make all the case managers be really involved, really care, and really have them follow through to make sure that all the staff working with my kid knows what they need to know to support him" (Angie, personal communication, May 8, 2017).

Magic Wand Summary

The 14 participants in this investigation—parents of children with disabilities—responded to a question that empowered them. I gave them a say into what they believe needs fixings with the special education process. Participants utilized their background knowledge and experiences to respond to the question without effort. The participants provided remarkably consistent responses. Magic Wand Themes included: (a) better/more communication; (b) more funding for tools, resources, and the quality and quantity of support personnel; (c) more accountability; (d) more follow through; (e) shorter duration between referral, testing, and support; and (f) specific characteristics of

those serving children with special needs, including individuals who are openmindedness, caring, and are involved.

Chapter Summary

In this chapter, I presented participant one-word summary perception of the special education process and their justifications for those perceptions. I also gave my participants a voice by asking them to identify what needed to change in their eyes with the special education process.

The 14 summary perceptions include *communicate*, *confused*, *follow-through*, *lacking*, *frustrating*, *disheartening*, *cookie-cutter*, *overwhelming*, *'They're doing their best*, *'effort*, and *useless*. Participants provided explanations to these perceptions that directly connect to the research questions of this investigation. To revisit them briefly, the focus of this research project surrounds parent perceptions of the special education framework. I asked a multi-part question which was designed to look at the discourse that parents of children with disabilities experience. I have intended to answer what was the function of the discourses these parents experienced, how the discourse functions as it acts on these parents, and to explain why the discourse functions in that uncovered way. As I based this project on grounded theory, I am also interested in uncovering any alternative explanations that the data might present. Critical moments of the special education framework have challenged my 14 parents. These experiences have solidified into summary perceptions of that process.

The 14 participants also responded to an empowerment question. I gave them a

voice into how we should repair the special education process. From their background knowledge and experiences, participants easily answered the question. Remarkably consistent themes emerged from their responses. These themes included: (a) better/more communication; (b) more funding for tools, resources, and the quality and quantity of support personnel; (c) more accountability; (d) more follow through; (e) shorter duration between referral, testing, and support; and (f) specific characteristics of those serving children with special needs, including individuals who are open-mindedness, caring, and are involved.

In the next chapter, I discuss the findings to Chapters IV, V, and VI. I discuss the limitations of this investigation, and I present implications for practice, professional development, teacher education, and curriculum development.

CHAPTER VII

DISCUSSION, LIMITATIONS, IMPLICATIONS, AND CONCLUSION

Overview

I designed this investigation to reveal, explore, and determine the functions of discourses that parents of children with disabilities encounter as they experience the formalized special education process. My intent with this investigation was to explore the meaning of special education from the perspective of parents who have or have had children go through the special education process. As such, my leading questions have been how do these discourses function? Do the discourses that parents of children with disabilities experience in the context of the special education process function as a tool to empower or disempower and whom does this discourse privilege? Likewise, do these discourses these parents experience function to alienate and marginalize or unite and value? I asked these specific questions because my broader goal has been to understand the perceptions of parents who have children with disabilities that arise from a set of entwined social relations embedded in systemic complexities and constraints—the formalized processes and mores that define the process of gaining access to special education.

To accomplish the objective of this dissertation, I provided the reader with an extensive review of the literature surrounding topics directly related to this investigation. In this discussion, I included CDT and four models of disability, specifically the *Social Model*, *Minority Model*, *Gap Model*, and *Medical Model* (Figure 1). The review also

covered discourse research on disability and parent perception research contextualized by special education. Within that discussion, I discussed reviews of the literature, one of which concerned 'involved' parents (Table 1) and another that explored culturally and linguistically diverse parent perceptions (Table 2). I also researched survey literature (Table 3), transition literature (Table 4), and membership and categorical literature (Table 5) to round out research positions on parent perceptions and special education. Last, I reported the publications concerning the primary themes of this investigation.

Importantly, within this discussion, I reviewed the *Systematic Change Framework* from the research of Kozleski and Smith, (2009) that describes a twenty-factor model form improving equity for students with a disability within the U.S. public educational system (Figure 3, Chapter II).

Additionally, to accomplish the objective of this dissertation, I developed the rationale behind this qualitative, exploratory, grounded theory case study. I argued for the use of CDA and selected CDT methodology and concepts to interpret the perceptions and revealed discourses surrounding parents whose children with disabilities and have encountered or experienced the special education process. I also explained my positionality, discussing how I have been both a parent and a professional within the special education process context; moreover, I revealed how I have hidden disabilities, and these have been a part of my life from day one.

In the first of three findings chapters, Survey Findings (Chapter IV), I documented how my participants responded to a survey designed to get them thinking about the special education process before the actual interview. Within the participant's

responses to this survey, they revealed and acknowledged their fears. Each parent had quality of life concerns for their child or children with disabilities. Most were concerned about their child's ability to socialize and communicate with peers and adults. They were more concerned about their child's ability to function at home and in the community than at school. After acknowledging their fears, the participants addressed how they might approach these concerns, most stating they would develop a plan with the school, and even more saying they would seek outside services. This fact, in my view, suggests that many of the participants are either not seeing the benefit of specialized instruction or they don't see sufficient progress and want more for their children than the school is willing or able to provide.

Participants also reported their perceptions about obtaining support. In general, participants perceived the difference between communicating with their child's teacher and with that of Evaluation Review/IEP team member participants. Most reported feeling like they could speak their mind in both situations; however, regarding productivity, most participants perceived communication with the teacher as a more productive experience than when communicating with special education staff. A higher proportion of participants reporting that special education team communication was 'not productive' reflected this fact.

Next, within the survey, participants revealed their attitudes about special education issues. Here, I asked them to put themselves in someone else's shoes and take on an 'other's' perspective. Within this data, there was, for example, a direct relationship to how participants perceive 'others' beliefs about students with disabilities and the

participants' attitudes about labels that were revealed during interviews and discussed in Chapter V, Interview Findings. More specifically, four of my 14 participants (28%) revealed a concern for *Labels*—the referential devices that can be 'helpful' or 'unhelpful' dependent upon one's point of view. Rex, for example, revealed, *Labels* are the latter, 'unhelpful,' stating that the "diagnosis was a hang-up for sure." (*Rex*, personal communication, June 24, 2017). He furthered this 'hang-up' with, "I feel like if you get a diagnosis, that's your life" (Rex, personal communication, June 24, 2017).

In Chapter IV, participants also revealed their views about the cost of special education within the schools. While unsure about how states or districts fund special education, they were sure of its place, value, and need for supporting children with disabilities. My participants tied funding in both the survey and their interview responses to issues of equity for their children with disabilities who require access to extra support.

Last, participants addressed the concepts behind the theme *Power*. Through categorical responses, participants responded to questions addressing *Power as Repression*, *Power as a Social Relation*, and *Productive Power*. While most participants indicated that they felt they had the same *Voice*, say, or authority in an Evaluation Review meeting or IEP meeting, some participants stated that they did not have the same *Power*. They felt *Repressed*, *Lacking Voice*. They did the listening. Responses to these questions draw a direct relationship to participants' discussions during the interview and their survey responses about feeling *Unheard*. In summary, chapter IV established that there exist concerns that parents with children with disabilities have when engaging in and interacting with the special education process. These concerns were clear, consistent,

and genuine.

In the second of my three findings chapters, Chapter V, I presented findings related to 14 semi structured interviews that occurred following the surveys. In each case, I drew from the participants' survey responses to assist the conversation, but not lead it. I wanted participants to have the opportunity to explain and discuss issues that they felt essential or diverged from the literature so that the reader could be informed. As stated previously, the survey, as indicated by several participants, got them thinking about their experiences and was a useful process; they reported feeling more prepared with more organized thoughts at the time of the interview.

It was within Chapter V that I demonstrated the emergence of six themes that arose from the discourses of 14 participants. First, to illustrate the highly critical nature of my participant's discourse toward the special education process, I provided an NVivo11 word-frequency analysis of their reactions regarding issues that surround the special education process (Figures 37 and 38). The most frequently counted word was 'frustrate.' This count included the suffix iterations, 'frustrated,' 'frustrating,' and 'frustration.' As the special education process has been around since 1974, this single piece of data suggests that we need to radically change or overhaul the hegemonic process of getting children into specialized instruction for the sake of the parents and their children with disabilities.

Also within Chapter V, I presented the theme *Power* which was the central and overriding theme expressed within the discourse of my 14 participants. These individuals referred to the *Power of Communication*, both *spoken* and *unspoken*. They discussed

Procedural Power and how their Lack of knowledge, Procedural knowledge, Experience, and Expertise affected their ability to garner services or efficiently advocate for their children with disabilities. Participants also discussed Power via Personal agendas and Authority, Power in number, and Working Relationship Power, and importantly how they gained Power or Empowerment through Knowledge or Self-education.

In considering some specifics of this investigation surrounding the theme *Power* as compared to other studies of a similar nature, the results of Scorgie (2015) are reflective of this research. I found issues of *Child Membership* in my investigation. Five of my parents (36%) discussed their concerns with *labels* and explained how their children had or might lose dignity as a result. Similarly, five parents (36%) also addressed their concerns about their child and his or her *separation from peers* (*segregation*), while three parents (21%) brought up *inappropriate membership placement*. Likewise, my parents discussed *differential treatment* of their children by teachers and peers. This differential treatment revealed itself via teachers through *humiliation* in front of their peers (1 participant), by being *outed* (2 participants), through lack *of appropriate support* (3 participants), *through inappropriate pedagogy* (3 participants), and *inconsistent support* (5 participants). Differential treatment of children by peers occurred in the form of *bullying*. These instances then of 'membership ambiguity' found within my study strengthen the content validity of my results.

Also, in this investigation, *Role Ambiguity* (Scorgie, 2015) revealed itself when parents discussed instances of a *Power Differentials* with professionals. Even though parents know their child best, parents felt as if they had diminished power. This theme

revealed itself when parents discussed *Lacking Power because of Professional Expertise* (9 participants), *Experience* (6 participants), and *Knowledge* (10 participants). Homework issues, on the other hand, were also discussed by parents in my investigation, but to a lesser extent (5 participants).

In line with the *Productive Power* that emerged from the discourse of my participants was the theme *Advocacy*. All 14 participants discussed *Advocacy* for their children and were represented by 114 separate coding instances. It is my view that this *Productive Power* or *Self-Education* that these participants engaged improved, enhanced, or strengthened their willingness to advocate actively and persistently for their children with disabilities. The participant discourse revealed instances of both successful and unsuccessful moments of *Advocacy*. It also exposed cases where children with disabilities were advocating for themselves and unsuccessful cases of advocacy that led to continued marginalization. My participants also discussed instances where the school or an agency supported their children with disabilities and when a school failed to support the needs of the child.

I also presented the theme *Dignity* in Chapter V. Participants discussed, on the one hand, how their children with disabilities *Gained Dignity* through employment opportunities, friendships, leadership, recognition, support, and training. On the other hand, participants discussed *Lost Dignity* for themselves and their children with disabilities. They felt judged and not believed during the special education process and interactions with team members. Children lost dignity through inappropriate placement and from being outed. Children also lost dignity through the abuse of power, through

bullying, through labels, by lack of fidelity in the educational program, through exclusion, and by the sequelae of the child's impairment.

In the analyzed discourses, the desire for *Equity* or *Equality* for my participants' child or children with disabilities emerged. Later in this chapter, I present how I approach (and suggest as an approach to) this nebulous, quintessential problem within special education. I discuss not only the *Systematic Change Framework* of Kozleski and Smith (2009) concerning the theme *Equity* and *Equality*, but I introduce how one can simplify this twenty-factor model, at least at the *Provider*, *School*, and *District levels* by following an *Ethical Leadership Model*. Leaders, professionals, and practitioners who engage this model are forced to consider the *ethics of justice*, *critique*, *care*, and *the profession* in their everyday actions. By considering these four ethical frames, one can better issues equity and equality to the best of one's (and societies) abilities for children with disabilities and parents of children with disabilities.

The last theme that I presented in Chapter V and that emerged from the discourse of my 14 participants was *Voice*. Participants noted situations when they felt like they *Had Voice* and instances when they were *Lacking Voice* within the special education process. This theme is troubling. It ties directly to all other issues uncovered in this investigation. If one holds the perception of *Lacking Voice*, there is *Inequity* in a system designed to treat all voices as equal. Likewise, if one has the impression of *Lacking Voice*, one loses *Dignity*: the feelings of being *Devalued* and *Unwanted* emerge.

Moreover, if one holds the perception of *Lacking Voice*, the process of standing up for what one believes in (i.e., *Advocating* for the constitutional rights of one's child) feels

more like a pointless exercise. And last, if one has the perception of *Lacking Voice*, one is being *Repressed* by the *Power* held by others, trapped in a hegemonic environment that remains in a state of *status quo*.

In Chapter VI, I presented my participants one-word summary statements about the special education process. These statements include the following: *communicate*, *confused*, *follow-through*, *lacking*, *frustrating*, *disheartening*, *cookie-cutter*, *overwhelming*, 'They're doing their best,' effort, and useless. As I have expressed, I am interested in how the discourse my participants experienced functions as it acts on these individuals. In my view, the discourse these participants encountered or experienced within the special education framework has been challenging for them. These discourses have solidified into profoundly critical summary perceptions of that process.

Evelyn's need is *Communication*. *Communication* is one of five factors that comprise an effective school (Marzano, 2003). The challenge, according to Marzano is that *Effective Communication* can be confounded by "legal restrictions, district policy" (p.48), as well as the history of the district. Marzano pointed out through work by Melaragno et al. (1981) that the most frequently used school-to-home communication systems remain newsletters, bulletins, and flyers which are not necessarily active forms of communication. With this type of connection, the parent is a receiver of information, and there is little opportunity to respond. Marzano also stated, however, it is the district's responsibility to initiate communication as parents are under no obligation to do so (p. 48). As such, Evelyn's need for *Effective Communication* so that she can be informed, know special education policy and law and be apprised of her son Sam's progress, is at

the mercy of a given district, school leader, or an individual practitioner. In other words, it will be up to them to want to change the culture of school communication for the better.

Sandy and Meagan described the special education process as 'confused.' They consider the discourse within the special education process Repressive. Details of Power as Repression (Foucault, 2003) load their stories. In Sandy's discourse, there was both a Lack of Effective Communication (see Marzano, 2003) and the problem of Power as Repression (Foucault, 2003). 'Confused,' to Sandy meant 'Ineffective Discourse with a parent,' 'Communication Lacking Clarity,' or 'Discursive Discourse.' Factors contributing to Sandy's discourse on Repression were many and varied. She encountered Power via Authority (i.e., the Lead Educational Authority, the 'gatekeeper,' and the special education teacher in charge of educating Sandy's daughter, Chelsea. She felt her daughter repressed by Power via Communication (Discursive jargon, policy, and procedure). Sandy encountered *Power via Expertise* (a professional degree held by the special education teacher) and *Power via Personal Agenda* ("my classroom" and the attempt to place Chelsea into a program that may or may not have support, rather than individualizing the education to meet Chelsea's specific needs). Meagan's spoke of the withholding of necessary information; her discourse revealed Power as Repression (Foucault, 2003). She experienced the repression from the factors *Power via Lack of* Knowledge and until her second child went through the process, Power via Lack of Experience. Meagan acted on this repressive power by doing research. She engaged in Productive Power (Foucault, 1990) as several of my participants did. She acquired Power via Knowledge which can arguably better allow Meagan to advocate for her children at

IEP meetings. Last, Meagan's discourse revealed a challenge of large organizations, the confusion that can occur between *Processes* and *Outcomes*.

Angie's need is follow through. In her discourse, she revealed the lack of communication between team members, but she also brings up an issue that organizations can experience when they focus on *Processes* rather than *Outcomes*. Bezos (2017) and Gold et al. (2013) discuss this problem that Angie encountered and suggest that organizations look at the outcomes they need (e.g., student success through follow-through), and build the processes to make that goal achievable. Angie believes that focusing on outcomes rather than processes is critical for children like her son, Timothy, whose disability is invisible.

Robert and Janet both described the special education process to be 'lacking.' In his discourse, Robert revealed the length of time it took for him and his wife to become Special Education savvy. Robert, who repeatedly showed he had a big heart and considered an *Other* first, expressed his concerns for minority populations in his state who may be dealing with the special education process, acknowledging the challenge of communicating necessary information to others who do not necessarily speak the language of instruction. Janet, on the other hand, discussed a system-wide failure. Her case is a perfect example of the need for districts to consider a model like the *Systematic Change Framework* of Kozleski and Smith (2009; see also Chapter II, Figure 3). Janet saw the problem as a workload issue, a funding issue, the multi-factorial problem of teacher motivation, burnout, and veteran teachers who refuse to change their educational teaching practices, and she connected her discourse to the need for upfront support—

adequate training and mentorship for student and first-year teachers. For Janet to see *Equity* emerge for her two daughters, Shawna and Maci, there would need to be systemic state, district, school, and teacher level changes.

Carrie is frustrated. Carrie expressed the frustration of delays and the frustration of the site specialist [IEP specialist] handing her a report from the school's diagnostician without explanation or discussion. She experienced a form of Repressive Power (Foucault, 2003) due to her working relationship. She expressed frustration at not hearing results; being uninformed, she felt marginalized. Carrie also tried to overcome this marginalization by investing considerable *Time* and *Effort* into her child's problem, Gaining Power through Knowledge. She also explained that the marginalization comes in part from limitations imposed on the teacher. That is, "they don't have the time to be that motivated, that interested, that caring, that committed to helping any student [emphasis added]" (Carrie, personal communication, May 24, 2017). In her story, Carrie worked at reframing the hegemonic discourse and replacing it with a platform of Advocacy. This Knowledge Power has the potential to reach her goal or create a level of understanding and thereby lessen or improve the alienation, marginalization, and *Power Inequities* that she encountered. In my view, Carrie's story is disheartening, because, in the end, she descends into the hegemonic discourse. Carrie justifies the district's marginalization of her and her son, Max, by indicating that the alienation, marginalization, and *Power Inequities* results from the *Lack of Financial Resources*, a money issue, nothing more.

Dave considers the special education process to be *inconsistent*. He experienced *Power* differentials via *Communication* and *Caring*. He also suffered the effect of

inadequate training. His text expressed the frustration of seeing his daughter alienated and marginalized.

The special education process disheartens Danielle. She experienced a *Power* differential through *Power via Procedure*. Even though she had referred her child early on, district policy put her child into a placeholder and acted on the request only when the time came. It made Danielle feel disheartened, marginalized by the required effort she perceived that it would take to support her child at home versus the energy required to obtain support within the school system. A compounding factor in Danielle's case was *Resource Scarcity*, a lack of qualified personnel to carry the testing forward.

Rebecca is wondering what happened to the Individual in the Individual Education Plan. She views the process as cookie-cutter. Her son suffered due to lack of an individualization education plan; her son, Garrett had been denied a FAPE with goals applicable to anyone. A denial of FAPE is an unambiguous method of suppressing and silencing those who cannot speak for themselves; it creates the definite potential for a de minimis education.

Rex ('They're Doing Their Best') and Joy ('Overwhelming') experienced discourse that served to disempower. They experienced Power via Authority and Power via Personal Agenda. Joy felt marginalized by the efforts of the district. As she stated, she was "a voice without a voice." The experience, context, and discourse served to alienate Joy's perspective.

Diane's view of the special education process is that of *Personal Effort*. She discussed a definite difference in *expectations*, family vs. that of the school. Diane's text

revealed how she felt *alienated* by the school. In Diane's eyes, Maddison was succeeding only because of the home support; the family had to sacrifice to support Maddison; she reported feeling the need to do this so that her daughter would not lose *Dignity* with her peers and be successful. She was seeking *Equity* and *Equality* for her child, and the school was not supporting this effort. As such, the family gave Maddison her entitled FAPE via home support.

Jennifer considers the special education process to be 'useless.' She discussed how her son was Losing Dignity by receiving special education support. Jennifer revealed within her discourse an Unsupportive Staff, Inappropriate Placement, Inappropriate Service Methodology/Pedagogy, and Separation from Peers for her son Luke.

Also in Chapter VI, I gave my 14 participants *Voice*—a chance for them to once and for all express themselves and define what they would change regarding the special education process. They utilized their background knowledge and experiences to respond to the question without effort. The participants provided remarkably consistent responses. The themes that emerged include: (a) better/more communication; (b) more funding for tools, resources, and the quality and quantity of support personnel; (c) more accountability; (d) more follow through; (e) shorter duration between referral, testing, and support; and (f) specific quality characteristics of those serving children with special needs, including individuals who are open-minded, caring, and involved.

In the remaining sections of this chapter, I discuss the conclusions and implications of this research and provide concluding remarks. To do this, I present the results as they relate to the four models of disability (Figure 1, Chapter II). Next, I

describe the results to Melé's (2014) *Organizational Tiered Model* for thinking about *Power*, *Ethics*, and *Working Relationships* (Figure 43, Chapter V). Then, I review the *Systematic Change Framework* from the research of Kozleski and Smith (2009; see also (Figure 3, Chapter II) concerning my results. Last, I present an *Ethical Framework for Leadership* (Shapiro & Stefkovitch, 2005). Within this Ethical Framework discussion, I offer a call to action and change. I will also address the limitations of my study, discuss my short- and long-term goals regarding this research, and address implications for future research.

Discussion of Findings

As discourses contribute to the construction of social identities and subject positions (Fairclough, 1992), they hold implications for both professionals within the special education process, parents of children with disabilities involved in that process, and by extension, children with disabilities, themselves. Throughout the investigation, discourses positioned parents and their children with disabilities in a variety of ways. Participant *Reactions* and explanations of encountered *Power* differentials demonstrated this differential. They spoke about the need for *Dignity* for themselves and their children with disabilities. They acknowledged the continual need to *Advocate* for their children with disabilities. They searched for *Equity* and *Equality* for the same. And they desired a *Voice* within the special education process. On the one hand, these discourses positioned parents and their children with disabilities as objects of *Repressive Power* (Foucault, 2003). This positioning was due to the parents' perceptions surrounding those they considered persons of *Authority*. Their discourses indicated that they, as parents (in the

eyes of those in power), lacked *Expertise*, *Experience*, or *Knowledge*. Likewise, their narratives showed that those in authority engaged in *Repressive Power* through a perceived lack of *Program Fidelity*, *Support*, *Communication*, and *Follow-Through*. Moreover, *Repressive Power* emerged in the discourses of parents surrounding perceived *Inappropriate Placement* for their children with disabilities, school-related *Bullying* their children encountered from students and staff, and the *Sequelae of the Impairments* which created instances of *Inequity*, *Outing*, and *Humiliation*. Simply put, the discourses surrounding *Repressive Power* within this investigation revealed cases of hegemony and marginalization for both my participants and their children with disabilities.

The discourses of these 14 parents also revealed that they perceived they and their children were objects of *Social Power* (Foucault, 2003). These participants expressed instances of feeling *Judged*, of *Not Being Believed*, *Lacking Voice*. The participants verbalized how their children had been *Outed*, *Humiliated*, and *Separated from Peers*. They also expressed a perceived permanent reduction in status that some saw attached to *Labels*. These discourses, in effect, limit the possibilities for parents and their children with disabilities.

On the other hand, these discourses were an avenue for *Productive Power*; that is, to *Advocate* for *Equity* and *Equality* for their children with disabilities, participants engaged in *Self-Education*. This self-education regarding district and state policy, special education procedure and law, as well as the child's disability allowed my participants to reduce these repressive differentials of *Power* expressed throughout this investigation.

Consistent with the belief that children with disabilities are entitled to a free and

appropriate public education, ESSA (2015/2016) mandates that parents should be involved in decision making and by extension, be active advocating members for their child or children with disabilities. Likewise, all members within the special education process should be accountable for how to educate a child with disabilities. As such, there is evidence suggesting a positive and direct correlation between the academic outcomes of a student and parent involvement is overwhelming (e.g., Deslandes, Royer, Potvin, & Leclerc, 1999; Marzano, 2003; McNeal, 1999; A. V. Shaver & Walls, 1998). Moreover, special education law and best practices surrounding implementation of that law—including the basics of referral, notification, tiered intervention, evaluations, the review process, document construction, planning, implementation, and reporting—supports, if not demands, parent-professional partnerships, collaboration, and the notion of shared power between parents and professionals in all aspects of special education decision-making.

Findings and Models of Disability

In Chapter II, Figure 1, I presented and discussed four models of disability. I had an interest in these models of disability because perspectives can change depending upon one's frame of reference. For example, it may be that a schools' inability to meet diverse student needs that, in the end, becomes a facilitator for disability as an identity and the concomitant placement in separate classrooms. Joy and Rex expressed this sentiment regarding their daughter Sierra, as did Sandy regarding Chelsea, her daughter. Skrtic (1995) stated that disability might be a matter of "not fitting the standard practices of the prevailing paradigm of a professional culture" (p. 214).

Participants, within this dissertation project, spoke about disability from all four frames of reference. For the *Social Model* of disability, participants referred to this model when discussing their wishes for the special education process (Chapter VI). Some participants sought more funding (Dave), including more "warm bodies" (Carrie, Janet), more qualified staff (Joy, Rex, Meagan), smaller caseloads and support for student accommodation needs (Diane), and support for incentives, training, training time, and tools (Janet). Grue (2011) discussed that through the *Social Model* of disability, one closely examines the "systemic factors that shape the meaning of disability, particularly those that have to do with political economy" (p. 538). These participants saw inequity and inequality for their children with disabilities as a function of the political economies within the classrooms, schools, districts, and states and they want that repaired.

Concerning the *Minority Model* of disability, Dave's discourse referred to this model when speaking about other minority populations in his state of residence, who, he felt, would be even more challenged by the special education process than he and his wife. Grue (2011) stated through the work of Breivik (2007) that with the minority model, "disability is explained as...a form of cultural otherness" (Grue, 2011, p. 539). In this research, no participants discussed or viewed their child or children's disability from the standpoint of a "cultural identity" marker (p. 539). Instead, my participants' discourses reflected quite the opposite. They revealed dislike and disdain for *labels*. There was a desire to distance their child or children from that identity. The discourses of Evelyn, Dave, Joy, Rex, and Jennifer, reflected this objection.

As discussed in Chapter II, the *Gap Model* of disability is an acknowledgment

that "a proportion of the population will at any given time have either impairments or illnesses that place certain restraints on their functional capacities" (Grue, 2011, p. 540). More specifically, disability is the gap between ones' capacities and societal and institutional opportunities (Darling-Hammond, 2010; Grue, 2011). As such, a disability gap in the schools can be addressed by specific policies or practices. For example, a school might provide a child with a smaller class size so that a teacher can attend to that child more. Alternatively, an instructional assistant might scaffold the child's instruction. Or, the school might accommodate and modify instructional practices (e.g., shortened assignments, larger print, extended time, frequent checks for understanding). These example practices reduce the gap between what the child is capable of and those institutional opportunities of general education instruction. They give a child with a disability the opportunity to demonstrate their skills and understanding of regular curricular content.

All participants addressed the *Gap Model* within the discourse by discussing what is being done to provide support for their child or children with disabilities. For example, Evelyn and Carrie explained needed support services for their sons, Sam and Max. Rex and Joy discussed speech-language therapy services for their daughter Sierra. Sandy presented the multiple supports in place for her daughter Chelsea. Grue (2011) stated that this model makes one "aware of state bureaucracies in the social construction of disability" (p. 540). Participants were keenly aware of this supposition in their revealed discourses, particularly when the "state bureaucracy" failed to follow-through or act on the legal document (IEP) designed specifically to close the gap. For example, if the

reader will recall, Carrie discussed the *humiliation* and *outing* that occurred when instructors failed to provide accommodations for her son, Max. Diane explained Maddison's accommodations for P.E. that were not followed and had placed her daughter's health at risk. And Jennifer's son Luke was given instructional language support that was inappropriate for his age, grade level, and capabilities as well as IEP goals that were general, not individualized.

Participants also addressed the *Medical Model* of disability in their discourses. In discussing the medical model in Chapter II, I noted that Grue (2011) referred to the medical model as the "nemesis" of the other models of disability (p. 540). It reduces "various aspects of disability to medically recognized phenomena" and "denies agency" to individuals with disabilities, reserving "power to medical professionals" (p. 540).

Evelyn, for example, utilizes the medical model in her discourse to describe her son's ADHD and how hyperactivity medication helped her son, Sam, focus. The drug allowed professionals to see him as a child who was gifted (and one who needed speech services) instead of as a child with behavior problem who bit and kicked.

As another example, Sandy's discourse revealed a mom in search for answers from both school and medical professionals for her daughter, Chelsea. Her discourses referred to "problems" and things that needed to be "fixed." She reported visiting her family pediatrician multiple times. School professionals, in the end, diagnosed her daughter with "dyslexia... developmental delay and...a phonetic hearing-speech-processing problem" (Sandy, personal communication, April 6, 2017).

I think just hearing how delayed she was in all the areas and you want to know why. Why is she so far behind? What did I do wrong? What can I do to fix it? Is

there a label or a diagnosis of something that way we can say, "Oh, this is why?" Was she autistic? Did she have a hearing problem? Is it a neurological problem? We took her to a neurologist. Nothing came out there. We took her to a doctor to get genetic testing, and they said that was unnecessary. We got her hearing checked multiple times. It's fine. Dad thought she had a memory problem and come to show, she doesn't, but sometimes it seems like she does. (Sandy, personal communication, April 6, 2017)

If the reader will recall, in considering the four models of disability, Grue (2011) noted that they all fail to provide a full account of disability, writing:

...the social model does not properly acknowledge biophysical causation; the minority model does not account for economic and political causation; and the gap model assumes to a utopian extent that the gap between ability and expectation can always be closed—that there is no need for a distinct social role of disability. (p. 541)

As mentioned before, (Grue, 2011) treated the medical model separately, stating it is "invalid as an explanatory instrument" (p. 541). Concerning the findings described within this dissertation project, none of the disability models adequately account for the six uncovered themes. That is, a single model of disability cannot sufficiently explain the concepts revealed within the discourses of participants when discussing the special education process—specifically, *Power* differentials, *Equity* and *Equality*, *Voice*, *Dignity*, *Advocacy*, and *Reactions*. It indicates that these four models, which did emerge within the participant discourses, are more a reflection of an individual's world knowledge, background, and opinion, than a way to explain the discourses that saturate the special education process. Nor do these models of disability provide a satisfactory way of resolving the issues noted throughout the dissertation research project as they relate to the special education process.

Strong Model of Special Education Process Discourses from the Parent Perspective: Repressive Lens

As mentioned at the beginning of this chapter and throughout this dissertation, I designed this investigation to reveal, explore, and determine the functions of discourse that parents of children with disabilities encounter as they experience the formalized special education process. My goal has been to examine the meaning of special education from the perspective of parents who have or have had children go through the special education process. The purpose, then, of this study was to develop a grounded theory that describes and explains the discourse within the special education process of public education. As such, my focus has been to find out how discourses function as they act on these individuals. And as reported in Chapter V, by engaging in the process of constant comparison, I discovered six consistent, discrete, yet related themes. These included Power, Advocacy, Equity and Equality, Voice, Dignity, and Reactions. I presented and discussed the theoretical underpinnings of these themes in Chapter II, Literature Review, and in Chapter V, Major Findings, I detailed the discourses behind the themes. In thinking specifically about the findings of this dissertation research project, in Figure 50, I pictorially offer a summary, generalized, answer to my research question.

This theoretical model of discourses emerged and revealed itself as I explored the parent perceptions data thoroughly, engaging in constant comparison. I compared codes and themes for consistency, repeatedly, checking definitions and instances between cases (participants) and within a case (participant), itself. More specifically, when I engaged in this process of reviewing themes between and within cases, I became aware of

Strong Model of Special Education Process Discourses from the Parent Perspective: Repressive Lens

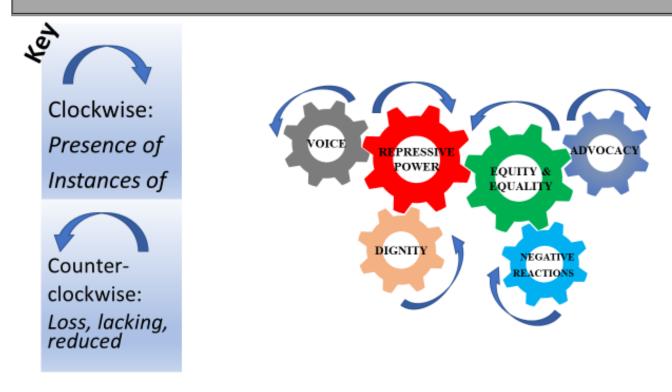


Figure 50. Strong model of special education process discourses from the parent perspective: Repressive lens.

relationships that existed between these six themes. To best visualize these relationships that emerged between the six discrete, yet related themes, I have graphically represented these concepts as interlocking, opposing gears. In Figure 50, the theme, *Repressive Power* and the theme *Equity and Equality* are represented pictorially by their size to the other themes. They are the primary themes (gears). *All participants revealed Repressive Power* (Foucault, 2003) in the discourse. When participants expressed *Repressive Power*, there were corresponding discourses describing *Equity and Equality* losses for the participants and their child or children with disabilities, as well as perceived loss of *Voice*, and *Dignity*. Arrows that go from right to left, indicate the concepts 'loss,' 'lacking,' or 'reduced'; arrows that go from left to right indicate the concepts 'presence of' or 'instances of.'

Also, I have pictorially represented in Figure 50, what occurred with *Advocacy* and *Reactions*. I observed through the discourses that when instances of *Repressive*Power were present, and Equity or Equality was lost or reduced, there were corresponding discourses surrounding attempts at *Advocacy* as well as more critical, profoundly Negative Reactions toward the special education process. As such, the relationship arrows around those themes (gears) demonstrate 'presence of' or 'instances of.'

Strong Model of Special Education Process Discourses from the Parent Perspective: Productive Lens

Equally important, here, but not represented in the above model of special education process discourses from parent perspectives (Figure 50) is what occurred

within the collected discourses when *Productive Power* (Foucault, 2003) emerged. If the reader will recall from discussions in Chapter V, *Productive Power* (or *Empowerment*) appeared when participants encountered instances of *Repressive Power*. Participants tried to lessen that *Repressive Power* through *Self-Education*, attempting to reduce or ameliorate the perceived *Inequities* that participants delineated in their discourses. As such, in Figure 51, I present, pictorially, a summary, generalized, explanation of what occurred with discourses when *Productive Power* was a factor.

In Figure 51, because participants sought a change to their situations within the special education process and engaged in *Productive Power* the relationship arrows for each theme are reversed. The gears go in the opposite direction. The reader should also note that there are now three primary themes (gears) as indicated by their size, *Productive Power*, *Repressive Power*, and *Equity and Equality*. When *these 14 participants* revealed Productive Power in the discourses, Repressive *Power* lessened. As *Repressive Power* reduced, the presence of corresponding discourses regarding improved *Equity and Equality* for my participants and their child or children with disabilities was evident. Additionally, as this occurred, discourses concerning the perception of having *Voice* and *Dignity* emerged. Moreover, the discourses revealed that when instances of *Repressive Power* lessened, and *Equity or Equality* was improved, the need for *Advocacy* attempts lessoned as well as a corresponding reduction in *Negative Reactions* (and a corresponding increase in positive reactions).

These models also indicate that discourses within the special education process are dynamic and fluid. They are bound by context and influenced by individual factors of

Strong Model of Special Education Process Discourses from the Parent Perspective: Productive Lens

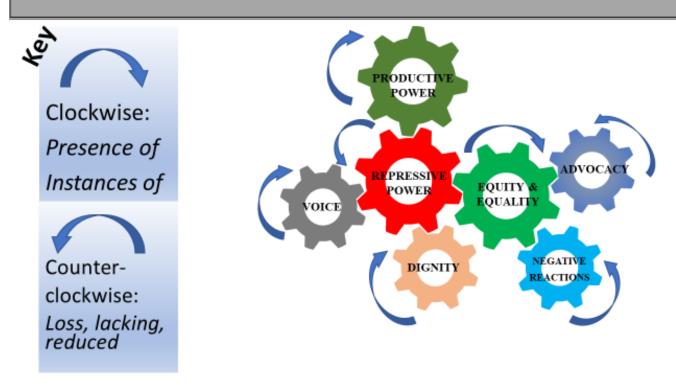


Figure 51. Strong model of special education process discourses from the parent perspective: Productive lens.

practitioners (e.g., training, experience, personality), school-level team culture, district-level culture, as well as state and federal education and funding priorities.

Findings and Organizational Tiered Model of Human Quality Treatment

In Chapter V, Figure 43, I introduced and discussed Melé's (2014)

Organizational Tiered Model of Human Quality Treatment. It provides a framework for thinking about Power, ethics, and working relationships.

I explained in the Chapter V discussion that with this model one could situate discourses, such as those found within the special education process, as they relate to levels of Human Quality Treatment. And as an example in Chapter V, I took Carrie's discourse and situated it within this model. I located her discourse at the lowest level in this model, Maltreatment. Abuse of Power (Repressive Power) characterized her conversation. In her discourse, the abuse of *Power* by the site specialist led to marginalization, an injustice. I then described the other levels of the model, explaining, for example, that *Indifference* involves *disrespect*. It occurs through lack of recognition (e.g., parents who 'voice' concerns but are not acknowledged). The middle level is Justice which involves having those in power show respect toward others and their rights. Justice would be shown, for example, by having an administrator following the law. Care is the fourth level: those in power show concern for other's interests and support them however they can. *Development* is Melé's (2014) highest level. Here, leaders help others grow. This level is collegial and friendship-based. Growth in self-esteem becomes an outcome.

Again, on the Tiers of this model, any of the discourses collected during this dissertation can conceivably be placed. Melé's (2014) model provides a concise way of thinking about discourse. The model does not, however, afford an educational leader, practitioner, district, or state level educational organization the *how* for modifying one's practice or behavior so that the discourses, such as those found in this dissertation project, can be resituated or reframed to higher levels on this model. In other words, with this model, one is left with general admonitions. That is, the practical application is absent. In my roles as a speech-language pathologist, teacher, or instructional coach, I am interested in making connections so that students or others understand *what* they are learning, why the learning is useful, and *how* to approach the learning process. It is a philosophy with roots in both John Dewey and Lev Vygotsky. Melé's (2014) model lacks those practical applications.

Findings and a Framework of Systematic Change

As I presented in Chapter II, Figure 3, Kozleski and Smith (2009) developed a *Systematic Change Framework* to improve equity for students with disabilities. While this model clearly and systematically spells out what needs to occur at the Federal, State, District, School, and Practitioner Level to improve equity for children with disabilities, it is a daunting model and likely unobtainable or not sustainable if one attempted all factors at once. More specifically, this model does not provide the actionable thoughts a superintendent, principal, or professional (practitioner) would find helpful or necessary to make it truly successful. In the discussion section of Kozleski and Smith (2009),

however, these researchers noted that school level leaders could impact and influence a school culture considerably. This impact can occur by the way school leaders connect with those who teach or provide services to students. It can also be felt by the way school level leaders interact with families, as well as the programs they support, and by what they consider essential when structuring daily life within the school. I wholeheartedly concur with their synopsis of what school-level leaders can impact and influence. As such, issues of equity and equality for children with disabilities in the schools boils down to a matter of values and ethical practice. I discuss this value in the following *Call for Action* summative discussion.

Call for Action: A Critical Stance Regarding These Grounded Dissertation Results

The results of this dissertation hold clear implications for professionals within the special education process, parents of children with disabilities involved in that process, and by extension, children with disabilities, themselves. Through this research, I demonstrate a dynamic, unmistakable, authentic interplay between the concepts of *Power, Equity and Equality, Voice, Dignity, Advocacy*, and the resultant *Reactions from parents*. That is the experienced discourses that underlie special education process distinctly contribute to the construction of social identities and subject positions (Fairclough, 1992) between parents and professionals.

Ignoring these issues is not the answer. To do so creates the uncomfortable and unfortunate space for marginalization, inequity, and hegemonic discourses that parents and their children with disabilities will have to continue to unjustly experience and

endure. To do so creates an avenue for lack of voice and loss of dignity. It also creates a path for bitterness and resentment toward those charged with helping children succeed academically and socially. It also burdens the parent. They must first self-educate before making headway with the process that holds *Power* over their child. To ignore means the profoundly troubling issues raised and described in this dissertation study will remain untouched and unchecked.

Two summative questions arise from this dissertation. The first problem is core to each of our inner beings or selves: what is it that we as teachers, practitioners, and leaders value? The second question, then, holds dear those core values from the first issue and asks: Where do we go from here and are we willing to dedicate the resources that it takes to address the things we value?

If a *value is a* "standard or principle by which one judges worth" (Shaver & Strong, 1982, pp. 17, 139), then *what is it* that we, as administrators, teachers, and practitioners, *find worthy*? As you read the following questions, listen to your inner voice: Is respecting what a parent has to say and making them an honest and genuine part of the educational team, something we should value? What is it worth to provide accommodations to a student with disabilities so that he or she can demonstrate academic and social success and so that student learning can occur? Do we value the provision of a FAPE (and all that that entails, such as not predetermining a child's disability)? Likewise, what is a child's self-esteem worth? What is respecting the value of others and academic and social success for a child with a disability, worth to you as an individual? By completing this simple exercise, you should know what is important to you when it

comes to the provision of equity, dignity, and voice for parents and their children with disabilities.

Values, then, tell us what is essential. They are our enduring preference. Values provide structure. Through values, we make decisions about right and wrong (Shaver & Strong, 1982). "Values," according to Shaver and Strong, "are the essential ingredient in defining a democratic society" (p. 166). Shaver and Strong add:

...core values of [a] society are recognized as basic in debating and judging public policy and in making judgments about the morality of intents and actions toward one's fellow citizens. It can be argued that certain attitudes—for example, discriminating attitudes toward minority groups—are nondemocratic because they are opposed to basic values. But note that attitudes are judged against values, not vice versa. And a rationale that is to be securely founded on an adequate conception of a democratic society must start from fundamental commitments, from values, not from attitudes. (p. 166)

By focusing on *value* as teachers, practitioners, and leaders, the potential payoff is considerable. Likewise, the payoff for *value* focus teaching, practice, and leadership would be of benefit to the parents and children with disabilities as described in this study, and the numerous others like them. For it is through "the conscious articulation, consideration, and testing of values as they apply to the classroom, and school setting [that ensures] teaching behavior [and leadership] is consistent with basic democratic values" (Shaver & Strong, 1982, p. 168).

Morrill (1980) tackles some of the thorny issues that come with my plea for dramatic change. Specifically, in his text, *Teaching Values in College*, he asks the following four sets of questions.

1. How do the proposals to teach values, ethics, and morality square with the prevailing academic temper of neutrality in values and the institutional commitment to serve as a forum for all ideas and values? In a pluralistic

- society, whose values and which morality and ethics are to be taught?
- 2. What specific subjects and pedagogical aims and strategies are involved in teaching values, morality, and ethics? Are these acceptable and realistic possibilities for most colleges and universities and their faculties?
- 3. What is the relationship between knowledge and action in moral and values education? Are there ways to bridge the well-established gap between knowing and doing the good? Can education really affect such things as values? Can and should the study of ethics make one in any sense a better person?
- 4. What does the basic terminology of a given approach signify? What assumptions do the various alternatives harbor regarding the nature of education, knowledge, and human experience? How do these premises shape an understanding of the purpose and means of ethics, moral education, and values education? (pp. 11-12)

While I cannot conceivably answer these questions within the context of this research project, they are the issues that departments within a college of education would have to consider as they prioritize their values concerning what is essential when preparing new educators, practitioners, or educational leaders for the workforce.

Within Morrill's (1980) list of questions, he raised ethics as an issue. Ethics, help us tell the difference between right and wrong (Shapiro & Stefkovitch, 2016). Ethics, according to Dewey (1902) are the set of rules that govern the behavior of a person, established by a group or culture. It is the "science that deals with conduct...right or wrong, good or bad" (Shapiro and Stefkovitch, 2016, p. 10). Together, values and ethics provide the foundation for sustainability within a culture or organization (Morrill, 1980).

I advocate for universities and colleges taking a hard look at their foundational principles and teach teachers, practitioners, and leaders from a values-and ethics-based framework. I ask this with sincerity and candor. I request this re-evaluation of principles from the standpoint of these documented results and the findings of others cited in this

work. I also request this re-evaluation on behalf of my participants. Likewise, I advocate for change from the standpoint of twenty-seven years of professional practice in which I have observed and seen the issues raised in this research with all too common occurrence. A value and ethics-based framework is the only conceivable way to make significant, clear, lasting change for the marginalized and to break the cycle of hegemonic discourses. It is how we, as an academic society, can confront these heartbreaking stories that my participants shared. It is how we can change the decades-old narrative.

If issues of equity and equality, voice, and dignity are a matter of ethical practice, then one must consider models of ethical leadership and practice that have practical applications to mitigate the many negative *Power*, *Voice*, *Dignity*, *Reactions*, and *Equity* and *Equality* discourses uncovered within the results of this dissertation research project. Shapiro and Stefkovitch (2016) provided an ethical leadership framework that works toward this goal and, I believe, can serve educational leaders, teachers, or practitioners well. That is, educators who follow an *Ethical Leadership Framework*, such as the one developed by Shapiro and Stefkovitch (2016), can make critical decisions about unfamiliar and complex dilemmas in their schools.

The framework presented by Shapiro and Stefkovitch (2016) involves four approaches to ethical analysis. These include the *ethics of justice*, *critique*, *care*, and *one's profession* (see Figure 52). Within each frame, different questions are posed, each serving to guide decision-making practices. I introduce these four approaches to ethical analysis briefly here. I then connect the approaches to the special education process and discourses. Last, I discuss how each frame relates to the *Systematic Change Framework*



Figure 52. Ethical leadership framework (Shapiro & Stefkovitch, 2005)

of Kozleski and Smith (2009), discussed in Chapter II.

The ethic of justice. The first frame of the *Ethical Leadership Framework* (Shapiro & Stefkovitch, 2016) is the *ethic of justice*. Shapiro and Stefkovitch, in discussing the work of Delgado (1995) wrote that this frame of ethics concerns rights and law. These authors note that it "is part of the liberal democratic tradition" (p. 11) and that it is "characterized by incrementalism, faith in the legal system, and hope for progress" (Delgado, 1995, p. 1). Shapiro and Stefkovitch also stated through the work of Strike (1991, p. 415) that the 'liberal' part focuses on "commitment to human freedom" (p. 11). The 'democratic' part, however, involves "procedures for making decisions that respect the equal sovereignty of the people" (Shapiro & Stefkovitch, p. 11 [citing Strike, 1991, p. 415]).

Importantly, Shapiro and Stefkovitch (2016) reflected on the origins of the Ethic of Justice through the work of Starratt (1994), describing how it arose from two schools of thought. The first includes philosophers such as Hobbs, Kant, Rawls, and Kohlberg;

the second, however, comprises the philosophers "Aristotle, Rousseau, Hegel, Marx, and Dewey" (p. 11). This background is important because the first school "considers the individual as central and sees social relationships as a type of a social contract where the individual, using human reason, gives up some rights for the good of the whole or for social justice" (p. 11). The second camp of philosophers, however, which includes Marx and Dewey, tend "to see society, rather than the individual, as central and seeks to teach individuals how to behave throughout their life within communities" (p. 11). In this latter understanding and tradition, the concept *justice* originates from "communal understandings" (Starratt, 1994, p. 50). As such, central to these two approaches of justice is the relationship between individuals and the state (Shapiro & Stefkovitch, 2016). Likewise, central to this research are the themes and theme relationships that emerged from the discourses of individuals as they interacted with the state.

Questions specific to the *ethic of justice* focus on issues related to individual rights and laws. To make decisions from this perspective, an educator, practitioner, or educational leader would ask the following questions: "Is there a law, right, or policy that relates to a particular case? If there is a law, right, or policy, should it be enforced? And if there is not a law, right, or policy, should there be one?" (Shapiro & Stefkovitch, 2016, p. 13). As such, when considering the special education process, discourses, and parents and their children with disabilities, an educator, practitioner, or leader would need to reflect on federal and state law when confronted with, for example, issues of predetermination, placement, service, FAPE, or general education classroom accommodations. Those who reflect on the rules and a situation, then, have an ethical choice (or choices) to consider.

These options involve one, or more, or all the following: *Best Interests of the Student*, *Standards of the Profession, Individual Professional Codes, Personal Codes of Ethics, Professional Code of Ethics, and Ethics of the Community* (Shapiro and Stefkovich, 2016). Choosing not to act on any or all the broad categories leaves the hegemonic discourses in a state of status quo and the educator, practitioner, or leader at risk for legal recourse through ethics and licensure boards as well as the legal system.

In considering the model presented through the work of Kozleski and Smith (2009; see also Figure 3), adhering to and practicing the *ethic of justice*, fulfills the factors listed in the two o'clock position of Kozleski and Smith's model (Figure 3). Specifically, this ethic addresses *Leadership for learning* at the *Practitioner Level*, *Governance*, *Leadership*, *and Accountability* at the *School Level*, and *Inclusive Leadership for Equity and Accountability* at the *District* and *State Levels*. The two-o'clock position of the *Systematic Change Framework* (Kozleski & Smith, 2009) involves adherence to not only the letter of the law but its spirit as well.

The ethic of critique. In considering the previous frame, the *ethic of justice*, Shapiro and Stefkovitch (2016) noted that many scholars, educators, and individuals who campaign to bring about social or political change dislike the justice frame. They find "tension between the ethic of justice, rights, and laws and the concept of democracy" (p. 13). These individuals, including many I have cited in this dissertation (Apple, 1996, 1997, 2013; Foucault 2003, 2012; Freire, 1970, 1993, 1998) critique not only the laws but the processes that declared them just (Shapiro & Stefkovitch, 2016).

Concerning the *ethic of critique*, the interest is not to accept "the ethic of those in

Power," but rather "challenge the status quo by seeking an ethic that will deal with inconsistencies, formulate the hard questions, and debate and challenge the issues" (Shapiro & Stefkovitch, 2016). Shapiro and Stefkovich then wrote:

Their intent is to awaken us to our own unstated values and make us realize how frequently our own morals may have been modified and possibly even corrupted over time. Not only do they force us to rethink important concepts such as democracy, but they also ask us to redefine and reframe other concepts such as privilege, power, culture, language, and even justice. (pp. 13-14)

Questions within the *ethic of critique* help sensitize educators, practitioners, and leaders to inequities of difference, including race, social class, gender, and disability. In making decisions from this perspective, Shapiro and Stefkovitch (2016) stated that the questions embedded in this ethical frame include: "Who makes the laws? Who benefits from the law, rule, or policy? Who has the power? Who are the silenced voices?" (p. 15). In reflecting on the questions within the *ethic of critique*, an educator, practitioner, or school leader can examine the practices within the special education process. If an education leader acknowledges and acts to eliminate differentials of power, then special education process meetings and conversation around children with disabilities can be restructured to support and provide ample opportunity for acknowledgment of and space for parent voice. To address the four levels of the Systematic Change Framework (Kozleski & Smith, 2009; see also Figure 3) at the 10 o'clock position—*Inquiry on* Equity in Schooling— one must consider, act on, and adhere to the ethic of critique. The ethic of critique also addresses the concepts in the practitioner and school rings. It targets teacher design and practices, group practice and professional learning, family-schoolcommunity participation and partnerships, design and assessment of learning standards,

equitable resource distribution, the culture of change and improvement, and structure and use of space and time. In summary, it is an ethic designed to question the system and put the best interests of the student at the forefront.

Applying the ethics of justice and critique to this grounded theory study. In Figure 53, I connect to the *ethics of justice of* and *critique* the results of this investigation. First, to the *ethic of justice*, I provide a few of the codes that consistently arose during the interviews. Participants discussed predetermination, inappropriate placement, inadequate service time, a FAPE, the need for teachers to use the prescribed accommodations, the need to follow-through, being accountable, governance, and being informed (leadership for learning). These codes all center around the application of federal law, student rights, and state and district policy. Next, I apply the second ethic, the *ethic of critique*. This ethic focuses on values and value judgments. Shaver and Strong (1982) in discussing Oliver and Shaver (1974) suggested that "values are our standards and principles for judging worth" (p. 17). That is, "they are the criteria by which [one judges] 'things' (people, objects, ideas, actions, and situations to be good, worthwhile, desirable, or, on the other hand, bad, worthless, despicable, or, of course somewhere in between these extremes (p. 17)." Value judgments, on the other hand, are the "assertions we make based on our values" (Shaver & Strong, p. 17). As such, value judgments involve the criterion that leads to judgment. And of course, the criteria of value judgments are all different. They fluctuate day-to-day. And are context dependent. Operational questions based on values and value judgments include, as they relate to this investigation: Does this student have adequate service time? Is space for this student appropriate? Is the classroom

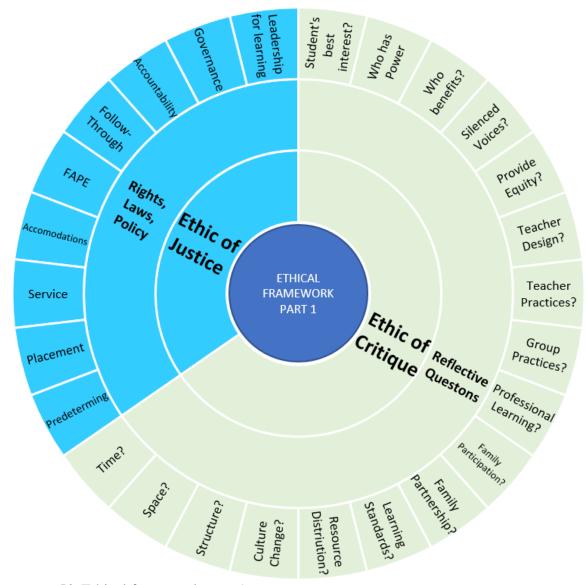


Figure 53. Ethical framework, part 1.

structure (physically and academically) appropriate? Are decisions possibly being made based on race, ethnicity, or socio-economic status? Are resources being distributed equitably? Are learning standards being applied appropriately? Is there a family partnership or even participation? Do I need to grow professionally to be of help to this student or do others? What are the group or teacher practices that affect this student in the

short-or long-term? Have I adequately designed the curriculum to support the student? Am I providing equity through the implementation of the written accommodations or should more be done? Are their silenced voices and if so, who are they? Who is benefiting from the decisions that I am making? Who has the power? And, is this decision in the student's best interest?

The above list of questions is not all-inclusive. But, these reflective questions within the *ethic of critique* are just as critical as applying the laws, rights, and policy within the *ethic of justice* to families of children with disabilities. They complement each other and, in the end, support student success by working toward reducing inequity, marginalization, and instances of hegemonic discourses.

The ethic of care. The third frame of the *Ethical Leadership Framework* (Shapiro & Stefkovitch, 2016), is the *ethic of care*. It grew out of the *ethic of justice*. In discussing Gilligan (1982), Shapiro and Stefkovitch (2016) noted Gilligan developed this ethic to foster "care, concern, and connection" (p.16) with others. It was developed to "to solve moral dilemmas" (Shapiro & Stefkovitch, 2016, p. 16). Moreover, the Ethic of Care was designed to challenge values of individuals, such as trust and loyalty. As such, through this *ethic*, one considers multiple voices when making decisions (Shapiro & Stefkovitch, 2016).

Briefly, in considering Melé's (2014) (Figure 53) *Organizational Tiered Model of Human Quality Treatment*, the concept *care*, is the fourth tier; at that level, those in power show concern for other's interests and support others however they can. Similarly, Noddings (1992) wrote: "The first job of schools is to care for our children" (p. xiv). As

such, in Noddings' hierarchical model, Care is at the highest tier.

Within the *ethic of care*, the questions educators, practitioners, and leaders should ask include:

Who will benefit from what I decide? Who will be hurt by my actions? What are the long-term effects of a decision I make today? And if I am helped by someone now, what should I do in the future about giving back to this individual or to society in general? (Shapiro & Stefkovitch, p. 18)

To utilize the *ethic of care* within the special education process, an educator, practitioner, or leader could ask themselves care related questions. For example, what are the long-term consequences of (a) predetermining a child's disability, (b) placing a child into specialized instruction or a self-contained, segregated classroom, (c) not following through, or (d) not listening to or attending to the parents' concerns? By considering, acting on, and adhering to the *ethic of care*, one addresses four levels of the *Systematic Change Framework* (Kozleski & Smith, 2009, see also Figure 3) at the 4- and 6 o'clock position. That is the *Ethic of Care* addresses and improves family, school, and district community partnerships. It could also set in motion a culture of change, renewal, and improvement through on-going group practice and professional learning.

Taken together, Shapiro and Stefkovitch (2016) considered the ethics of justice, critique, and care as complementary and not incompatible. These researchers stated through the work of Starratt (1994) that these ethics are interwoven themes, much like the interwoven themes of this dissertation—each one acting and connecting with the other. By blending them, one has a "richer, more complete ethic" (Shapiro & Stefkovitch, 2016, p. 19).

The ethic of the profession. The final and fourth frame of the *Ethical Leadership*

Framework described by Shapiro and Stefkovitch (2016) is the *ethic of the profession*. What is unique about this ethic is that it incorporates "those moral aspects unique to the profession and the questions that arise as educational leaders become more aware of their own personal and professional codes of ethics" (Shapiro & Stefkovitch, 2016, p. 19). This ethic at its core is *the best interests of the student*. Summarizing a field of researchers, Shapiro and Stefkovich wrote:

Frequent confrontations with moral dilemmas become even more complex as dilemmas increasingly involve a variety of student populations, parents, and communities comprising diversity in broad terms that extend well beyond categories of race and ethnicity. In this respect, differences encompassing cultural categories of race and ethnicity, religion, social class, gender, disability, and sexual orientation as well as individual differences that may take into account learning styles, exceptionalities, and age often cannot be ignored. (p. 26)

Unfortunately, there is no definition of *best interests of the student*. As such, teachers, practitioners, and leaders justify their interests by claiming that a decision they made is in the interest of the student (Walker, 1998, as cited in Shapiro and Stefkovitch, 2016). If the reader will recall, in Chapter V, under the heading *Power via personal agenda*, I explained that this happened to Joy and Rex's daughter Sierra, a child with an expressive-receptive language disorder. They encountered this *Power* when their special education director confronted them. This individual held *Expertise Power* and a *Personal Agenda*. The agenda was to get Joy and Rex to accept the label of autism and a self-contained, segregated classroom placement for their daughter. As stated by Rex:

I believe their agenda was to get rid of the disruption in class and so the regular classroom could proceed as they're supposed to, and *Sierra* could wither on the vine in the Special Ed room. He was pushing that agenda to get funding and to get *Sierra* into Special Ed full-time. (Rex, personal communication, June 24, 2017)

In that section, I also discussed *Power* and *Motives* through Marshall (1990) who

argued that individuals need power though they deny the need's existence. I contended that by acknowledging the power motive (Marshall, 1990), one becomes self-aware and even self-critical of one's motives, ideologies, and beliefs. If one attends to the *ethics of the profession*, one becomes self-aware and self-critical. Marshall's discussion about the problem of power is akin to the moral dilemmas that situate the questions within the *ethic of the profession*.

Shapiro and Stefkovitch (2016) stated that the questions within this ethical approach include, "What would the profession expect me to do? What does the community expect me to do? And, what should I do based on the best interests of the students, who may be diverse in their composition and needs?" (p. 27). By considering, acting on, and adhering to the *ethic of the profession*, one can address levels of the *Systematic Change Framework* (Kozleski & Smith, 2009; see also Figure 3) at the 6-, 8-, and 12-o'clock position.

This ethic addresses and improves family, school, and district community partnerships. It also addresses design, structure, space, time, and infrastructure. And last, it speaks to classroom design and teacher practices and equitable resource distribution.

Applying the Ethic of Care and Profession to this grounded theory study. In Figure 54, I connect the results to the *ethic* of *care* and *profession*. First, had professionals, leaders, teachers, or practitioners asked themselves the *ethic of care* questions, I purport that many codes within this dissertation would not have occurred. *Ethic of care* questions address *humiliation*, *wrong placement*, *inadequate methods*, *self-esteem*, *outing*, *non-fidelity of programming*, *quality of life concerns*, *bullying*,

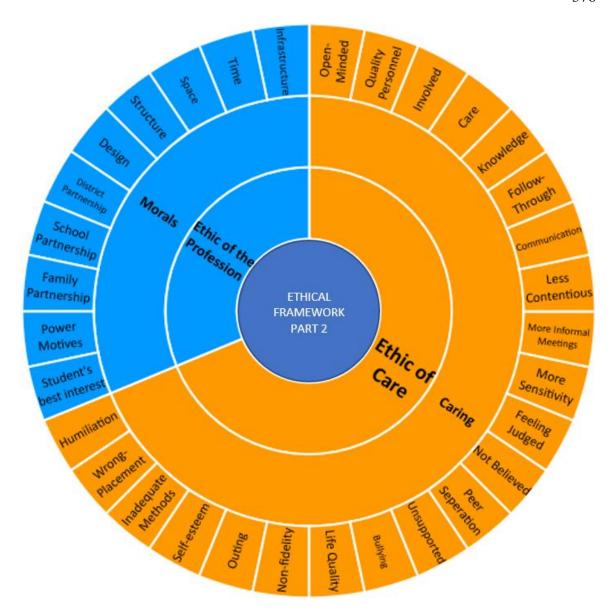


Figure 54. Ethical framework, part 2.

unsupported feelings, peer separation, not being believed, feeling judged, a need for sensitivity, less-contentious-more-informal meetings, clear-consistent-genuine communication, lack of follow-through, provision of knowledge, care and empathy, involvement, quality personnel, and open-mindedness. There would be no space for those codes with that ethic as a core value of those who provide service to children with

disabilities or their parents.

Likewise, had leaders, teachers, educators, or practitioners considered and applied the ethics of their specific professions, they would have met the best interests of the students. If the reader will recall, I introduced the core ethic of my career profession Speech-Language Pathology, at the beginning of this dissertation. I stated, "Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally..." (American Speech-Language-Hearing Association, 2016). By following this core ethic, I as a practitioner or leader would tackle issues that impede the Best Interests of the Student. These concerns include infrastructure, time-frequency-andgrouping allotted for services, and the appropriateness of space and curricular structure. These matters also include the *design* of the student's day, goals, and programming. These issues further include district partnerships with other agencies to offer optimal services and school partnerships with businesses and community members to provide employment, funding or services. Last, these matters include family partnerships to ensure and promote carryover over school programming, power motives, and those personal agendas that put the professional's interests first, rather than the student.

Again, the above list is not all-inclusive. I do provide these issues, however, as a point of discussion, and also as a starting point for serious consideration. I contend that universities and colleges must consider a values approach and an ethical framework as the bedrock for higher-education learning. They need to be the foundational principles that move teacher, practitioner, and leadership education forward within a university or college program. This approach would move conversations within public schools toward

the possibility of removing inequity, marginalization, and instances of hegemonic discourses. This bedrock thinking means that this *call for action* involves more than a section of course on diversity in education or special education issues. To be successful, it needs to run pervasively through the educational, practitioner, and leadership curricula. It is the only way to make lasting change. These individuals need to face value decisions early on and begin the process of rationale-building so that they can be well-equipped with values and ethics as they enter the workforce. Speaking from experience, Utah State University only touched upon ethics and values during my programming. This fact includes my Master's program in Speech-Language Pathology through the Department of Communicative Disorders, as I earned my Administrative-Supervisory Credential through the School of Teacher Education and Leadership, and during my doctoral program within the same school. This approach just wasn't the focus of the curriculum. Instead, I gathered these values and ethics through my background, being fortunate to have parents who were both educators and equipped with thick, moral backbones. They expected their students to understand and face value decisions and make ethical choices.

Following the practice of a model like the *Ethical Leadership Framework* introduced by Shapiro and Stefkovitch (2016) can assist educators, practitioners, educational leaders, the parents these individuals serve, and, by extension, children with disabilities. This model can mitigate and improve a lot of equity and equality issues exposed and expressed through the discourses of the participants within this document.

Goals, Intended Audience, and Project Significance

In the following sections, I address my short-and long-term goals, the intended

audience of this project, and this project's significance. As stated in the introduction of this chapter and throughout this document, I intended to explore the meaning of special education from the perspective of parents who have or have had children go through the special education process. I wanted to know how discourses function. Did they, for example, empower or disempower? Did the discourses serve to privilege a person or group? How and when? Likewise, did the discourses of my parents in this study experienced function to alienate, marginalize, unite, or value? The questions have been and continue to matter as I have experienced and witnessed uncomfortable moments during the special education process where discourse was poorly or inadequately delivered and served to disempower, alienate, and marginalize parents and their children with disabilities. I have also experienced well-presented information; the discourse empowered, united, and valued parents. As such, I have had both short- and long-term goals that this project is helping me fulfill.

Short-term goal. To begin, my short-term goal of this project was to empower parents of children with disabilities. I met this goal using the standpoint of grounded theory and selected methodology within critical ethnography. I was "less focused on time in the field or on the extent of data and more on the active collaboration between the researcher and the participants during the study" (Creswell, 2012, p. 478). In considerations before this investigation, I suspected from personal experience and through the pilot research data that I might encounter discourse that revealed issues related to *Power*, ethics, special education law, hegemony, marginalization, voice, and struggles with equity for children with disabilities. As such, I required the option of

reflexivity with the participant to educate and empower participants following expressed or revealed injustices. Moreover, as a Speech-Language Pathologist, it is my ethical duty to "hold paramount the welfare of those I serve professionally" (American Speech-Language-Hearing Association, 2016, p. 4). As critical ethnography may help bring change that affects the lives of participants, "the participants need to be involved in learning about themselves and steps [that] need to be taken to improve their equity, to provide empowerment, or to lessen their oppression" (Creswell, 2012, p. 478). I designed the interview questions to explore reflectively parents' attitudes, feelings, and beliefs as well as what they know and understand about the special education process. Due to my ethical beliefs and practices, I found myself reflexively engaging with most of the participants. I provided advocacy and education to reduce issues of marginalization or disempowerment. This engaged positionality aligns with the social justice component of CDT; it is a method for affording dignity to parents and their children with disabilities (Mažeikienė & Ruškė, 2011).

Long-term goal. My long-term goal for this project has been to utilize the themes and relationships that emerged to improve other's "understanding and use of knowledge" (Kincheloe, 2008, p. 10). This teaching will help "educators and teachers reconstruct their work, so it facilitates the empowerment of all students" (Kincheloe, 2008, p. 9). Knowing that alienation occurs from educational jargon, deficit-based views of children, and *Power* differentials between a "professional" and a "parent," one can work to reframe one's discourse and that of others within these contexts or in other environments as they occur.

Audience of long-term goal. In conjunction with the long-term goal, then, the intended audiences of this investigation are state, district, and school-level administrators, special education directors, special education teachers, and practitioners such as related service providers, school psychologists, and teachers. As indicated previously, the U.S. Department of Education reports that as of the 2011-12 school year, 6.4 million children and youth—12.9% of the general student population ages 3 to 21—received special education services (U.S. Department of Education, National Center for Education Statistics, 2015). As indicated previously, recent research has highlighted marginalization and alienation of parents and their children with disabilities throughout the delivery of special education processes and procedures. The results of this dissertation research project amplify and strengthen the body of work currently within the literature. My results demonstrate participants are definitively frustrated with the special education process. All 14 participants interviewed revealed discourses relating to *Power* differentials. Hegemony within the special education framework appears entrenched. The fact that my 14 interview participants came from five different districts within two regions of the U.S., one with a strong economy and one that is faltering, strengthens this supposition. Additionally, all participants expressed the discourse of Advocacy and revealed successful and unsuccessful advocacy attempts. Participants also reflected on concepts surrounding Dignity. They discussed how their children with disabilities gained dignity through employment opportunities, friendships, leadership, recognition, support, and training. On the other hand, parents lost dignity from feeling judged and not being believed. They noted that their children lost dignity through inappropriate placement, by

being Outed, and through abuse of power, bullying, and labels. Their children also lost dignity by lack of fidelity in the educational program, through exclusion, and by the sequelae of the impairment. My participants expressed the desire for Equity or Equality for their children with disabilities. I discussed this theme above within the context of a Systematic Change Framework and an Ethical Leadership Framework. And participants noted instances when they had Voice and Lacked Voice within the special education process.

Long-term goal, part one. One element of my long-term goal, then, is to inform at least one administrator and staff at one school so that they understand how discourses and function to privilege, empower, disempower, marginalize, unite, and value others, specifically when interacting with parents of children with disabilities.

Long-term goal, part two. The second element of my long-term goal is to provide training on this topic at a district-level training and state and national education-related conferences.

Long-term goal, part three. As I place value on maintaining, tracking, and keeping data, the third element of my long-term goal is to develop a user-friendly rubric and matrix that teachers and administrators could use during special education process interactions with parents. Its design would track and chart discourse instance types during IEP meetings; this data could then be utilized to inform and train staff during collaboration meetings until self-awareness occurs.

Long-term goal, part four. The last element of my long-term goal is to develop statewide implementation of training for elimination or reduction of discourses that serve

to privilege school staff and marginalize, disempower, and alienate parents and their children with disabilities by extension during the special education process.

Project Significance

By implementing this proposed project and acting on the short-term goal, I had the opportunity to provide empowerment to parents using critical ethnography (Creswell, 2012) during each case study conducted. This reflexive empowerment and engagement may bring change that affects the lives of these parents as they are "involved in learning about themselves and steps [that] need to be taken to improve their equity, to provide empowerment" (p. 5). Also, by moving forward on the four parts of the long-term goal, I now can assist educators and teachers so that they can "reconstruct their work, so it facilitates the empowerment to all students" (Kincheloe, 2008, p. 9) and parents of children with disabilities. The general aim of this goal is to systematically understand parental perspectives during the special education process and inform. And while not every school or team presents information as described, the themes and codes that emerged from the research questions provide valuable and transferable information to teachers, administrators, directors, and superintendents. It creates the opportunity for the goal of removing power imbalance, inequity, inequality, dominance, repression, hegemony, victimization, and lack of voice. Individuals, teams, districts, or agencies could use this data to carefully consider and evaluate their own experiences. These individuals could, for example, evaluate how and when they or others present information. These individuals could also consider how to improve information and service delivery. Individuals could examine whether parents are in the know, aware of the process, aware of potential limitations, timelines, or just have a clear and genuine understanding of what will occur when their child moves through the special education process. The individuals could also empower parents so that they can advocate strongly for the needs of their children with disabilities.

Limitations

This research, like any other, is subject to limitations. I utilized CDA to document conceptualizations of discourses experienced by 14 participants who have encountered the special education process. With respect to the special education process, the use of CDA as a tool lacked in the literature. However, to protect the anonymity of my participants, I did not examine specific effects of these conceptualizations on the children with disabilities, nor did I collect opposing or alternative perspectives (i.e., from other team members). Also, I did not examine or test the relationships that emerged and were or as presented in Figures 50 and 51 of this grounded theory dissertation project; instead, I set out to describe the observed themes and relationships. In other words, I did not examine special education placement, teacher judgment in decisions, parent involvement, factors used to determine disability or school-level factors such as pressure to provide services.

Another limitation is the size of the research sample. I based the decision to use a small sample (of up 20 participants) on many factors, including time limitations, a lackluster budget, and my personal experience in specialized instruction. The difficulty in obtaining district cooperation, agency cooperation, and the general reluctance of potential participants to commit their time to this project were clear obstacles. My original intent

was to utilize a large metropolitan school district within the southwestern U.S. That did not occur, however, due to lack of cooperation. Instead, I had to settle on the snowball method to recruit most of my participants. As such, all but one participant identified themselves as White, limiting the transferability of these findings. To this investigations credit, however, the 14 participants came from diverse districts (urban, suburban, rural, and small town) and backgrounds, providing remarkably consistent narrative discourses about the special education process.

Despite the noted limitations, this study makes an important contribution to the research literature on the use of CDA as a tool for examining parent discourses. I demonstrated through CDA (Figure 50) that when discourses of *Repressive Power* occurred, there were corresponding discourses describing *Equity and Equality* losses for the participants and their child or children with disabilities, as well as perceived loss of *Voice*, and *Dignity*. I also observed through Critical Discourse Analysis that when discourses of *Repressive Power* were present, and *there was* a perceived loss of Equity or Equality, there were corresponding discourses surrounding attempts at *Advocacy* as well as more critical, *Negative Reactions* toward the special education process.

Furthermore, I demonstrated (Figure 51) that because participants sought a change to their situations within the special education process and engaged in *Productive Power* the relationships for each theme reversed. That is, when discourses of *Productive Power* occurred, *Repressive Power* lessened. As *Repressive Power* lessened, discourses of improved *Equity and Equality* for my participants and their child or children with disabilities was clear. At the same time, discourses of having *Voice* and *Dignity* emerged.

Additionally, as *Repressive Power* lessoned, and *Equity or Equality* improved, there was less need for *Advocacy* and *Negative Reactions* (and a corresponding change in positive reactions).

I also tried to show in the developed models that discourses within the special education process are dynamic and fluid. They are bound by context and influenced by individual factors of practitioners (e.g., training, experience, personality), school-level team culture, district-level culture, as well as state and federal education and funding priorities. As such, this investigation might mainly be transferable to individuals, practitioners, districts, and situations reflected through the descriptions of this research project.

Implications for Practice

The results of this investigation and discussion regarding a need for values-and ethics-centered teaching and leadership are important for special education teams, practitioners, teachers, and school leaders. The discourses of parents within the special education process reveal that perceived Repressive Power frequently challenges them. It results in high levels of frustration, a lack of voice in the process, loss of dignity, and the perception that inequity and inequality exist for them and their children with disabilities. They also perceived the need to have to unjustly advocate for their child or children when there was lack of required action or follow-through on the part of the school, notably when the IEP document was in place. As stated in this discussion section, most, if not all the critical discourses revealed during this research arose from professionals ignoring or, at best, forgetting, their ethical obligations toward practice within their profession. As

such, a place to start, at the least, is for professionals to become aware of and acknowledge "the power motive" (Marshall, 1990). It means reflexive practice: being self-aware and even self-critical of one's motives, ideologies, and beliefs. Professionals who attend to the *ethics of the profession* (Shapiro & Stefkovitch, 2016) may become self-aware of their actions and self-critical, implementing needed actions to change and modify behavior and practices.

Implications for Professional Development

Within the context of the special education process, the results of this investigation and discussion above regarding a need for ethical practice are of genuine importance for special education teams, practitioners, teachers, and school leaders specific to professional development. Perceived Repressive Power within the special education process discourses frequently challenges parents and their child*ren with disabilities*. It results in high levels of frustration, a lack of voice in the process, loss of dignity, and the perception that inequity and inequality exist for them and their children with disabilities. As such, states, districts, and schools must provide value-centered and ethical practice training such as that developed by Shapiro and Stefkovitch (2016). It would benefit educators, practitioners and school leaders who experience the special education process engage in reflexive practice and implement practices that circumvent the repressive discourses revealed through this research.

Implications for Teacher Education

The results of this investigation suggest that there is a gap in teacher education

surrounding reflexive, ethical practice. Why else would school leaders, practitioners, and educators fall into the practice of hegemonic, discursive discourse? While ethics is a subject touched upon in most teacher, practitioner, and leadership programs, it is not necessarily a primary focus or a required course. However, as Shapiro and Stefkovitch (2016) wrote, "In the 21st century, as society becomes even more demographically diverse, educators will, more than ever, need to be able to develop, foster, and lead tolerant and democratic schools" (p. 4). As such, "through the study of ethics" educators, practitioners, and leaders "will be better prepared to recognize, reflect on, and appreciate differences" (p. 4). This need did not go unnoticed by my participants. Several (*Robert*, *Meagan*, *Danielle*, and *Diane*) wished for better *Accountability*, *Janet* asked for more *training*, and *Dave* asked for more *open-minded personnel*.

Implications for Curriculum Development

As the results of this investigation suggest a gap in teacher education or preparation surrounding reflexive, ethical practice, it would be of great benefit to include curriculum in a teacher, practitioner, or administrative leadership program that focuses on the issues of ethics, diversity, tolerance, and inclusive democratic education.

Reviewing the quote in the above paragraph, Shapiro and Stefkovitch (2016) stated it is now, more than ever, necessary to engage in this kind of training—reflexive, critical thinking and engagement—due to the divisive climate and culture that is currently thriving in our society.

Conclusions and Recommendations for Future Research

The purpose of this study was to develop a grounded theory that describes and explains the discourse within the special education process of public education. I designed this investigation to reveal, explore, and determine the functions of discourse that parents of children with disabilities encounter as they experience the formalized special education process. The themes *Repressive Power*, *Productive Power*, *Voice*, *Dignity*, *Equity* and *Equality*, *Advocacy*, and *Reactions* emerged. As I explored the themes within and between participants, relationships between themes emerged as well. From this grounded theory project, two theoretical models of special education process discourses emerged from the participants' interviews.

The first model reflects (Figure 50) what occurs when Repressive Power operates and acts on parents within the special education process. When *Repressive Power* occurred, there were corresponding discourses describing *Equity and Equality* losses for the participants and their child or children with disabilities, as well as perceived loss of *Voice*, and *Dignity*. Moreover, when *Repressive Power* was present, and *there* was perceived lost or reduced Equity or Equality, there were corresponding discourses surrounding attempts at *Advocacy* as well as more critical, highly *Negative Reactions* toward the special education process.

In the second model (Figure 51), I demonstrated that because participants sought a change to their situations within the special education process and engaged in *Productive Power* the relationships for each theme reversed. That is, when discourses of *Productive Power* occurred, *Repressive Power* lessoned. As *Repressive Power* lessoned,

discourses of improved *Equity and Equality* for my participants and their child or children with disabilities was clear. At the same time, discourses of having *Voice* and *Dignity* emerged. Additionally, as *Repressive Power* lessoned, and *Equity or Equality* improved, there was less need for *Advocacy* and *Negative Reactions* (and a corresponding change in positive reactions).

These models also indicate that discourses within the special education process are dynamic and fluid. They are bound by context and influenced by individual factors of practitioners (e.g., training, experience, personality), school-level team culture, district-level culture, as well as state and federal education and funding priorities.

As I conducted this research project, several additional questions remain unanswered. The first set of questions concern the discourses perceived by parents and the results of this investigation: first, do the discourses, codes, and themes obtained in this research match discourses obtained from culturally, ethnically, and linguistically diverse populations? Second, would the models revealed by the relationships in this investigation between the themes be the same in different population groups? And third, do the discourses that parents reveal match those of professionals within the special education process, and if not, how are they different? The second set of questions concerns the issues of ethics: Do teachers, practitioners, or educational leaders who receive extensive training in the field of ethics and diversity sensitivity fair better regarding the discourses surrounding parent perceptions than those who do not? Do educators, practitioners, or educational leaders who attend district level or school level professional development concerning ethics and diversity sensitivity fare better than the

same groups who do not receive the training regarding the discourses surrounding parent perceptions? Do educators, practitioners, or leaders who engage in reflexive, and ethical practices alter the models, themes, or relationships discussed within the findings of this dissertation?

Chapter Summary

In this chapter, I discussed the findings of my grounded theory research study as presented in Chapter IV, V, and VI. I also explored the results with models of disability. I then introduced the findings via two theoretical models that show the uncovered themes and theme relationships regarding special education process discourses. One model focuses on Repressive Power while the other demonstrates the addition of Productive *Power.* Following the presentation of these models of special education process discourses from parent perspectives, I discussed the findings with a Tiered Model of Human Quality Treatment, a Framework of Systematic Change, and a Framework of Ethical Leadership. Within that discussion, I presented my Call to Action. I argued that a value-oriented and ethical framework that involves the ethics *Justice*, *Critique*, *Care*, and the *Profession* can act as the bedrock—the foundational principles that molds teacher, practitioner, and leadership education within a university or college program. This approach would, I believe, move conversations within public schools toward the goal of improving situations of inequity, marginalization, and reducing hegemonic discourses. This type of bedrock thinking means more than a section of a course on diversity in education or special education issues. Pervasive implementation is crucial for successful

implementation. It must run through educational, practitioner, and leadership curricula. It is the only way to make lasting change. This approach would mitigate and ameliorate a lot of equity and equality issues exposed and expressed through the discourses of the participants within this document.

Next, I presented my goals, my intended audience, and the significance of this research project. I developed a Call for Action in the sincere hope that these results will awaken higher-education institutions, legislators, state educational agencies, districts, and individual schools. I followed this up with discussions concerning the limitations of this investigation and the implications for practice, professional development, teacher education, and curriculum development. Last, I provided the reader or researcher with some directional questions for future research to further explore perceptions of parents within the special education process and to improve special education process practices.

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APPENDICES

Pilot Study Coding Data

Pilot Study Coding Data

Participant	Brenda	Denise	Debbie	Grace	<u>Lisa</u>	Maggie
Power Imbalance	p. 1 ¶ 7 p. 2 ¶ 5 p. 3 ¶ 2, 3, 4 p. 4 ¶ 4 p. 5 ¶ 2	p. 1 ¶ 7 p. 2 ¶ 5 p. 3 ¶ 2, 3, 4 p. 4 ¶ 4 p. 5 ¶ 2	p. 2 ¶ 3, 4, 5, 6 p. 3 ¶ 5 p. 4 ¶ 5	p. 3 ¶ 4, 5, 6, 7	p. 1 ¶ 2 p. 5 ¶ 7 p. 6 ¶ 1	p. 3¶5
Empowerment	p. 3 ¶ 5 p. 5 ¶ 1, 3	p. 2 ¶ 1, 7 p. 3 ¶ 4, 5 p. 4 ¶ 1 p. 5 ¶ 5, 6 p. 6 ¶ 1, 7, 8	p. 5 ¶ 4 p. 4 ¶ 4	p.4 ¶ 12 p.5 ¶ 1, 2	p. 2 ¶ 1 p. 3 ¶ 5, 6 p. 4 ¶ 3, 5, 6, 8 p. 5 ¶ 2, 4, 6 p. 6 ¶ 1, 3 p. 7 ¶ 3 p. 7 ¶ 4	p.1 ¶ 2, 9 p. 2 ¶ 4 p. 3 ¶ 2 p. 4 ¶ 3
Inequality		p. 3 ¶ 1, 8 p. 4 ¶ 2 p. 5 ¶ 3	p. 3 ¶ 6	p. 4¶3,7	p. 6¶3	
Equality	p. 2 ¶ 9, 10 p. 3 ¶ 1, 5 p. 5 ¶ 1				p. 4 ¶ 8 p. 5 ¶ 3 p. 6 ¶ 4, 5	p. 2 ¶ 2, 4 p. 3 ¶ 1 p. 3 ¶ 6
Inequity			p. 3 ¶ 6 p. 4 ¶ 8	p.2 ¶ 2 p.4 ¶ 5, 9, 10	p. 1 ¶ 2 p. 2 ¶ 1 p. 5 ¶ 6	
Equity	p. 2 ¶ 6, 9 p. 3 ¶ 2, 5, 6, 7 p. 4 ¶ 5, 9, 13 p. 5 ¶ 1, 2	p. 2 ¶ 4 p. 3 ¶ 1, 8 p. 5 ¶ 5 p. 6 ¶ 1, 4				p. 1 ¶ 6, 8, 9 p. 2 ¶ 1, 4 p. 3 ¶ 7 p. 4 ¶ 1
Dominance		p. 5¶2		p. 3¶7	p. 1¶2	
Repression		p. 1 ¶ 8 p. 2 ¶ 2, 6 p. 3 ¶ 1 p. 3 ¶ 4 p. 4 ¶ 1 p. 5 ¶ 5 p. 6 ¶ 4	p. 2 ¶ 3, 4, 5, 6 p. 3 ¶ 15 p. 4 ¶ 7 p. 4 ¶ 8	p. 3 ¶ 3	p. 1 ¶ 2 p. 3 ¶ 3 p. 5 ¶ 6 p. 6 ¶ 3 p. 7 ¶ 3	p. 3 ¶ 7
Hegemony	p. 2 ¶ 1 p. 3 ¶ 3, 4	p. 2 ¶ 5 p. 4 ¶3, 4	p. 3 ¶ 6, 7, 14	p. 3¶8,9	p. 1 ¶ 2 p. 2 ¶ 1 p. 3 ¶ 3 p. 4 ¶ 9 p. 5 ¶ 6 p. 6 ¶ 1	p. 3 ¶ 6
Victimization	p. 4¶3	p. 1 ¶ 7 p. 2 ¶ 2, 5 p. 3 ¶ 8 p. 4 ¶ 1, 2 p. 6 ¶ 8	p. 2 ¶ 3, 4, 5, 6 p. 4 ¶ 3	p. 2 ¶ 4 p. 3 ¶ 4, 5 p. 4 ¶ 3, 8, 10	p. 1 ¶ 2 p. 2 ¶ 1 p. 3 ¶ 2, 3, 4 p 5 ¶ 5, 6 p. 7 ¶ 3	p. 1¶3
Lack of Voice		p. 3 ¶ 1, 6 p. 4 ¶ 1, 4 p. 5 ¶ 3 p. 6 ¶ 4	p. 2 ¶ 3, 4, 5, 6 p. 3 ¶ 8, 15 p. 4 ¶ 7 p. 5 ¶ 1	p. 2 ¶ 4 p. 3 ¶ 6, 11 p. 4 ¶ 4, 5, 6, 8	p. 1 ¶ 2 p. 6 ¶ 1, 2	
Voice	p. 4¶8	p. 3¶1	p. 4¶4		p. 4 ¶ 9 p. 6 ¶ 3	p. 2 ¶ 4, 5, 6, 7 p. 3 ¶ 4, 6 p. 4 ¶ 1 p. 4 ¶ 3
Disability Category	Autism	SLD	DD	Autism	Multiple	SLI
		Relieved	Okay-Mom Aggravated-Dad	Devastated	Relieved - Emily Anxious - Dylan	Regret Guilt Shame Relief Nervous Apprehension

USU Institutional Review Board Approval Letter



Institutional Review Board

USU Assurance: FWA#00003308

Exemption #2 Certificate of Exemption



Melanie Domenech Rodriguez, IRB

FROM: Chair

Nicole Vouvalis, IRB Administrator

To: Steven Camicia, William Strong

Date: February 20, 2017

Protocol #: 8229

Title:

A Critical Case Study Of Parental Perceptions Surrounding Formalized Special Education

Processes

The Institutional Review Board has determined that the above-referenced study is exempt from review under federal guidelines 45 CFR Part 46.101(b) category #2:

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (a) information obtained is recorded in such a manner that human subjects can be identified, directly or through the identifiers linked to the subjects: and (b) any disclosure of human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

This exemption is valid for three years from the date of this correspondence, after which the study will be closed. If the research will extend beyond three years, it is your responsibility as the Principal Investigator to notify the IRB before the study's expiration date and submit a new application to continue the research. Research activities that continue beyond the expiration date without new certification of exempt status will be in violation of those federal guidelines which permit the exempt status.

As part of the IRB's quality assurance procedures, this research may be randomly selected for continuing review during the three year period of exemption. If so, you will receive a request for completion of a Protocol Status Report during the month of the anniversary date of this certification.

In all cases, it is your responsibility to notify the IRB prior to making any changes to the study by submitting an Amendment/Modification request. This will document whether or not the study still meets the requirements for exempt status under federal regulations.

Upon receipt of this memo, you may begin your research. If you have questions, please call the IRB office at (435) 797-1821 or email to irb@usu.edu.

The IRB wishes you success with your research.

4460 Old Main Hill

(435)

797-

1821

Letter of Cooperation



February 17, 2017

Dear William Eric Strong:

has received and reviewed the research protocol for your project entitled "A Critical Case Study of Parental Perceptions Surrounding Formalized Special Education Processes". It appears that you are taking the proper ethical and legal safeguards to protect participants and have submitted our Researcher Statement of Assurances form that you will do so.

Furthermore has received approval from the Executive Director of Special Services for you to conduct the research.

Therefore grants permission for you to conduct this study under the conditions set forth in your research protocol. Please inform this office if you should need to amend the protocol. Furthermore, tetains the right to rescind permission at any time in the future.

Given that the protocol indicates that you will not have interaction with any students, you do not need to submit a background security clearance to the district. However, this requirement could change if your protocol were to change.

Sincerely,



Recruitment Flyer, English

PARTICIPANTS NEEDED

A Critical Case Study of Parental Perceptions Surrounding Formalized Special Education Processes

Steven Camicia, PhD William Eric Strong, M.S., CCC-SLP, A/S-C

Principal Investigator Student Researcher (801-518-3193) (208-243-4143)

(steven.camicia@usu.edu) (eric.strong@aggiemail.usu.edu)

Breaking the news to parents about a child's impairments is a delicate process. It can be done well or not well. Likewise, discussing levels of performance or a plan of action for children with disabilities requires care and tact.

Participants needed: Up to <u>Twenty</u> parents of children who are in special education or who have gone through the special education process.

The purpose of this qualitative study is to explore the perceptions of parents of children with disabilities regarding the special education process in the schools and the discourses they encounter.

The investigators wish to critically understand parent perceptions of the discourse that occurs within the formalized special education process and how these discourses function to privilege, empower, disempower, alienate and marginalize, or unite and value.

We are asking you to participate in an on-line 50 item **survey** and a **Semistructured interview**, the primary method of data collection. The surveys will guide the interview and consist of open-ended questions about specific aspects of parents' perceptions regarding the special education process and the way school professionals say things or talk to them. **Interviews are expected to last around 60 minutes**. Following the data analysis, the investigator will contact the participant to **review** descriptions, themes, and overall case analysis to ensure perceptions, thoughts, and data are represented accurately. This final step should take **15 to 30 minutes**. For participation in this study, a \$20.00 Visa gift card will be offered.

If you have other questions or research-related problems, you may reach (PI) Steven Camicia at 801-518-3193, steven.camicia@usu.edu. IRB PROTOCOL #: 8229

Recruitment Flyer, Spanish

SE BUSCAN PARTICIPANTES

Un crítico estudio de caso sobre las percepciones parentales con respecto a los procesos formalizados de la educación especial

Steven Camicia, PhD

Investigador principal (801-518-3193)

(steven.camicia@usu.edu)

William Eric Strong, M.S., CCC-SLP, A/S-C

Investigador estudiantil (208-243-4143)

(eric.strong@aggiemail.usu.edu)

Informar a los padres de los discapacidades de su hijo/a es un proceso delicado. Se puede hacer bien o mal. Así mismo, hablar de los niveles de capacidad o de un plan de acción para un niño/a con discapacidades requiere cuidado y tacto.

Se buscan participantes: Hasta <u>Veinte</u> padres de niños/as que están en educación especial o quienes han pasado por el proceso de la educación especial.

El propósito de esta investigación cualitativa es explorar las percepciones de los padres de niño/as con discapacidades con respecto al proceso de la educación especial en las escuelas y los discursos que encuentran.

Los investigadores quieren entender críticamente las percepciones de los padres sobre el discurso que ocurra dentro del proceso formalizado de la educación especial y cómo estos discursos funcionan para favorecer, dar o quitarle el poder, alienar y marginar, o unir y valorar.

Estamos pidiendo que usted participe en **entrevistas semiestructuradas**, lo cual será el método primario de la recolección de datos. Las entrevistas serán guiadas por preguntas abiertas sobre aspectos específicos de la percepciones de los padres con respecto a la educación especial y la manera de que los profesionales escolares dicen cosas o se comunican con ellos. **Las entrevistas deben durar 60 minutos.** A cada participante se le pedirá que complete **una encuesta** que puede ser enviada por correo electrónico o enviada de vuelta al investigador. Después del análisis de los datos, el investigador se pondrá en contacto con el participante para **revisar** las descripciones, los temas y el análisis general del caso para asegurar que las percepciones, los pensamientos y los datos se representan con precisión. Este ultimo paso debe durar **15** a **30 minutos**. Por participar en este estudio, se ofrecerá una tarjeta visa de regalo que vale \$20.00

Si tiene otras preguntas o problemas con respecto a la investigación, puede contactar (PI) Steven Camicia al 801-518-3193, steven.camicia@usu.edu. IRB PROTOCOL #: 8229

Letter of Informed Consent, English, Revised

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v.10 9.1.2016

Informed Consent

A Critical Case Study of Parental Perceptions Surrounding Formalized Special Education Processes

Introduction

You are invited to participate in a research study conducted by Steven Camicia, Ph.D. and Eric Strong, Speech-Language Pathologist, Ph.C., in the Department of Teacher Education and Leadership at Utah State University. The purpose of this research is to learn more about the perceptions of parents of children with disabilities have regarding the special education process in the schools and the discourses they encounter. You have been asked to take part because you have a child who is or who has gone through the special education process. There will be approximately 20 participants from the Albuquerque metropolitan, surrounding areas, and Cache Valley/Cache County Utah. There will be approximately 20 total participants in this research study.

This form includes detailed information on the research to help you decide whether to participate in this research. Please read it carefully and ask any questions you have before you agree to participate.

Procedure:

Your participation will involve one face-to-face semi-structured interview, lasting approximately 60 minutes. The face-to-face interview will take place during a mutually convenient time in your home, in a neutral place of your choosing, or via on-line conferencing (e.g., Skype). The interviews will involve open-ended questions about your perceptions regarding the special education process and the way school professionals say things or talk to you. At the interview, the researcher will ask you if it is okay to record the conversation only for the purposes of clearly remembering what you say. You will also be asked to complete a survey which can be emailed or mailed back to the investigator. After data collection is complete the investigator will contact you and review with you descriptions, the developed themes, and the case analysis as a method of ensuring data is accurately represented. This review process will take 15 to 30 minutes. We anticipate that up to 20 people will participate in this research study at this site, and that a total of up to 20 people will participate among all 2 sites.

Risks

This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those you encounter in everyday activities. The foreseeable risks or discomforts include The foreseeable risks or discomforts include unease or anxiety as you are discussing your perceptions about the special education process and the discourses you encounter. In order to minimize those risks and discomforts, the researchers will engage with you reflexively to help you learn about what know and don't know about the special education process and to provide empowerment or advocacy, as necessary; you may also freely end or withdraw from the study, interview, and/or survey if you feel it is necessary to do so. If you have a bad research-related experience or are injured in any way during your participation, please contact the principal investigator, Steven Camicia, of this study right away at 801-518-3193 or steven.camicia@usu.edu..

Benefits

Participation in this study may or not to help you personally. Questions are designed, however, so that there is active collaboration between the researcher and participant. Through the process of taking about your experiences you may better understand them. This process may help you learn more about yourself and steps that need to be taken to improve equity, provide empowerment, or lesson oppression. The interview questions will explore reflectively your attitudes, feelings, and beliefs as well as what you know and understand about the special education process; these questions will also explore reflexively attitudes, feelings, and beliefs as well as what you don't know and don't understand about the special education process. As part of that reflexive process, the

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investigator will engage in advocacy and education to reduce issues of marginalization or disempowerment, if needed.

More broadly, the research results may also help the investigators learn more about how parents perceive the special education process and discourse of professionals involved in special education. We hope that in the future other people might benefit from this study through improved understanding of parent perceptions as they encounter or go through the special education process.

Confidentiality

The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study. However, it may be possible for someone to recognize your particular story or responses. To minimize this risk, we will take the following steps: (1) as we collect your information, your research data will be kept confidential, consistent with federal and state regulations; only the investigator, Steven Camicia and student investigator, Eric Strong will have access to the data; (2) no names of participants will be used (pseudonyms will be created for you and your child); (3) as such, during the digitally recorded interview and the completed survey, pseudonyms will be used to protect identity; you will be referred to using a pseudonym and no clearly distinguishing information will be revealed in resulting documents; (4) the location (city, district, state, and school) of the study will not be revealed nor any information that could lead to your specific identity; (5) only through the use of an identification key, the researcher will be able to link information to your identity; (6) only the researchers will have access to the identification key, and (7) to protect your privacy, personal, identifiable information will be removed from study documents and replaced with a study identifier.

We will collect Digital audio recordings during the interview, email may be utilized to help coordinate time and date of the interview, and Qualtrics, a web-based survey site, will be utilized for survey responses. Survey responses and digital recordings will be destroyed once transcription and coding of responses is complete. This information will be securely stored in a restricted-access folder on Box.com, an encrypted, cloud-based storage system. Physical content (printed transcripts) and (survey data) will be kept in a locked drawer in a restricted-access office. Identifying information will be stored separately from data and will be kept for a period of no more than five years from the date the investigation ends.

It is unlikely, but possible, that others (Utah State University, or state or federal officials) may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so.

The research team works to ensure confidentiality to the degree permitted by technology. It is possible, although unlikely, that unauthorized individuals could gain access to your responses because you are responding online. However, your participation in this online survey involves risks similar to a person's everyday use of the internet.

Voluntary Participation, Withdrawal [and Costs]

Your participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by contacting Eric Strong, Student Researcher, at 208-243-4143 or by sending an email to eric.strong@aggiemail.usu.edu. If you choose to withdraw after we have already collected information about you, we will delete all electronic data and destroy any information pertaining to your case. If you decide not to participate, the services your child receives from your school and school district will not be affected in any way, now, or in the future.

The researchers may choose to terminate your participation in this research study if you are unable to fulfill the needed commitment to the interview and survey.

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Compensation

For your full participation in this research study which includes an interview, a survey, and a follow-up call, you will receive a twenty dollar (\$20.00) Visa gift card. Participation in this research is entirely voluntary. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study, or if you stop participating at any time, you will receive partial compensation for your time as gratitude. If you decide to withdraw from the study at any time, please contact Eric Strong, student researcher at 208-243-4143.

Findings & Future Participation

Once the research study is complete, the researchers will email and call you with the findings of the study, including individual categories and themes (results) relating to your participation as a way of checking to confirm the accuracy within the data and to share the investigation findings.

The researchers would like to keep your contact information in order to invite you to participate in future research studies. If you would like them to keep your contact information, please initial here: ______. This information will be entered into an excel spreadsheet that is completely separated from anything to do with this research study and maintained for a period of five years in a restricted-access folder on Box.com. You can contact the Principal Investigator at any time to be removed from this list.

IRB Review

The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator at 801-518-3193 or steven.camicia@usu.edu. If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or <a href="mailto:irreduced-ir

Director at (435) 797-	-0567 or <u>irb@usu.edu</u> .	Pleaseoaffix: an electronic signature						
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Steven Carringa			₩iÞliæm³Eri&Strong					
Principal Investigator			Student Investigator					
801-518-3193; stever	n.camicia@usu.edu		208-243-4143; <u>eric.stro</u>	ong@aggiemail.usu.edu	Ī			
Informed Consent								
			indicate that you under o. You also agree that you					
might have, and are c retain a copy of this fo		our participation	in the study if you choo	ose to do so. Please be	sure to			
Participant's	Signature,	Participant's	Name, Print	ed, Date				
Phone number		_						
Email where we can co	ontact vou. if needed	_						

Letter of Informed Consent, Spanish

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Consentimiento Informado

Un crítico estudio de caso sobre las percepciones parentales con respecto a los procesos formalizados de la educación especial

Introducción

Usted está invitado/a a participar en un estudio de investigación realizado por Steven Camica, Ph.D. y Eric Strong, Patólogo del Habla-Lenguaje, Ph.C., en el Departamento de Formación Docente y Liderazgo de Utah State University. El propósito de esta investigación es conocer más acerca de las percepciones que tienen los padres de niños/as con discapacidades sobre el proceso de educación especial en las escuelas y los discursos que encuentran. Se le ha pedido participar porque usted tiene un hijo o una hija quien está en el proceso de educación especial o quien ha pasado por ello. Habrá aproximadamente 20 participantes del área metropolitana de Albuquerque y sus alrededores. Habrá aproximadamente 20 participantes totales en este estudio de investigación.

Este formulario incluye información detallada sobre la investigación para ayudarle a decidir si quiere participar en esta investigación. Por favor, léalo atentamente y haga cualquier pregunta que tenga antes de dar su consentimiento para participar.

Procedimientos

Su participación involucrará una entrevista semiestructurada en persona, con una duración de aproximadamente 60 minutos. La entrevista en persona se llevará a cabo durante un tiempo cual es mutualmente conveniente en su hogar, un lugar neutral que usted escoja, o a través de una conferencia en línea (e.g., Skype). Las entrevistas incluirán preguntas abiertas sobre sus percepciones con respecto al proceso de educación especial y la manera de que los profesionales escolares dicen cosas o se comunican con usted. En la entrevista, el investigador le preguntará si está bien que grabe la conversación sólo por el motivo de recordar claramente lo que usted dice. También se le pedirá que complete una encuesta que puede ser enviada por correo electrónico o enviada de vuelta al investigador. Al completar la recolección de datos el investigador se pondrá en contacto con usted para revisar con usted las descripciones, los temas desarrollados y el análisis del caso como método para asegurar que los datos se representan con exactitud. Este proceso de revisión durará 15 a 30 minutos. Anticipamos que hasta 20 personas participarán en este estudio de investigación en este sitio, y que un total de hasta 20 personas participarán entre los 2 sitios.

Riesgos

Este es un estudio de investigación de riesgo mínimo. Eso quiere decir que los riesgos de participar no son más probables ni más graves que los que se encuentran en actividades cotidianas. Los riesgos o incomodidades predecibles incluyen: inquietud o ansiedad mientras de que usted habla de sus percepciones sobre el proceso de educación y los discursos que usted encuentra. Para minimizar esos riesgos e incomodidades, los investigadores se comprometerán con usted reflexivamente para ayudarle a aprender de lo que sabe y no sabe sobre el proceso de educación especial y proveer empoderamiento o apoyar, como sea necesario; también usted está libre a terminar o retirarse del estudio, entrevista y / o encuesta si considera que es necesario. Si tiene una mala experiencia relacionada con la investigación o está lastimado/a de cualquier manera durante su participación, por favor contacte el investigador principal Steven Camicia de este estudio inmediatamente al 801-518-3193 o steven camicia@usu.edu.

Beneficio

Más generalmente, los resultados de la investigación también pueden ayudar a los investigadores a aprender más acerca de cómo los padres perciben el proceso de educación especial y el discurso de los profesionales

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involucrados en la educación especial. Esperamos que en el futuro otras personas se beneficien de este estudio a través de un mejor entendimiento de las percepciones de los padres cuando encuentran el proceso de educación especial o pasan por ello.

Confidencialidad

Los investigadores harán todo lo posible para asegurar que la información que usted proporcione como participante en este estudio permanezca confidencial. Su identidad no será revelada en ninguna publicación, presentación o informe que resulte de este estudio de investigación. Sin embargo, es posible que alguien reconozca su historia particular o sus respuestas. Para minimizar este riesgo, tomaremos las siguientes precauciones: (1) a medida que recopilamos su información, sus datos de investigación serán mantenidos confidenciales, de acuerdo con las regulaciones federales y estatales; sólo el investigador, Steven Camicia y el investigador estudiantil , Eric Strong, tendrán acceso a los datos; (2) ningún nombre de los participantes será utilizado (seudónimos serán creados para usted y su hijo/a); (3) como tal, durante la entrevista grabada digitalmente y la encuesta completada, se usarán seudónimos para proteger la identidad; usted se referirá por un seudónimo y ninguna información suya claramente distintiva será revelada en los documentos que resultan; (4) no se revelará la ubicación (cuidad, distrito, estado y escuela) del estudio ni ninguna información que puede indicar su identidad especifica; (5) el investigadore podrá vincular la información con su identidad sólo con el uso de una clave de identificación; (6) solo los investigadores tendrán acceso a la clave de identificación y (7) para proteger su privacidad, la información personal e identificable será borrada de los documentos del estudio y reemplazada con un identificador del estudio.

Recolectaremos grabaciones digitales de audio durante la entrevista, se podrá utilizar el correo electrónico para ayudar a coordinar la hora y la fecha de la entrevista, y Qualtrics, un sitio web de encuestas, será utilizado para las respuestas de la encuesta. Las respuestas de las encuestas y las grabaciones digitales serán destruidas al completar la transcripción y codificación de las respuestas. Las grabaciones de audio se enviarán a un servicio de transcripción que está certificado por CITI, lo que significa que la confidencialidad de la información será mantenida. Esta información se almacenará de forma segura en una carpeta de acceso restringido en Box.com, un sistema de almacenamiento codificado y basado en la nube. El contenido físico (transcripciones imprimidas) y (datos de la encuesta) se mantendrán en un cajón con llave en una oficina de acceso restringido. La información identificable será almacenada aparte de los datos y no más tarde que el 2 de febrero de 2020.

Es poco probable, pero posible, que personas (de Utah State University o funcionarios estatales o federales) nos pidan que compartamos la información del estudio que usted nos proporcione para asegurarse de que la investigación se llevó a cabo de manera segura y apropiada. Solo compartiremos la información de usted si la ley o la política nos obliga.

El equipo de investigación se esfuerza para asegurar la confidencialidad al grado posible por la tecnología. Es posible, aunque poco probable, que personas no autorizadas puedan acceder a sus respuestas porque usted está respondiendo en línea. Sin embargo, su participación en esta encuesta en línea implica riesgos parecidos a los del uso de internet cotidiano de una persona.

Participación Voluntaria, Retirada [y Costos]

Su participación en esta investigación es completamente voluntaria. Si ahora usted da su consentimiento para participar y cambia de opinión después, puede retirarse en cualquier momento al contactar a Eric Strong, Investigador Estudiantil, al 208-243-4143 o enviando un correo electrónico a eric.strong@aggiemail.usu.edu. Si decide retirarse después de que ya hayamos recopilado información sobre usted, borraremos todos los datos electrónicos y destruiremos cualquier información relacionada con su caso. Si decide no participar, los servicios que su hijo/a recibe de su escuela y del distrito escolar no serán afectados de ninguna manera, no ahora ni en el futuro.



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Los investigadores pueden optar por terminar su participación en este estudio de investigación si usted no puede cumplir con el compromiso necesario a la entrevista y la encuesta.

Compensación

Por su participación completa en este estudio de investigación la cual incluye una entrevista, una encuesta y una llamada de seguimiento, usted recibirá una tarjeta visa de regalo que vale veinte dólares (\$ 20.00). La participación en esta investigación es totalmente voluntaria. Si usted decide participar en esta investigación, puede dejar de participar en cualquier momento. Si usted decide no participar en este estudio, o si deja de participar en cualquier momento, recibirá una compensación parcial por su tiempo como agradecimiento. Si decide retirarse del estudio en cualquier momento, por favor comuníquese con Eric Strong, investigador estudiantil al 208-243-4143.

Resultados & Participación Futura

Una vez que el estudio de investigación esté completo, los investigadores le enviarán un correo electrónico y le llamarán con las conclusiones del estudio, incluyendo categorías individuales y temas (resultados) relacionados con su participación como forma de confirmar la exactitud de los datos y para compartir con usted las recomendaciones de la investigación.

A los investigadores les gustaría mantener la información de contacto de usted para invitarle a participar en futuros estudios de investigación. Si desea que mantengan su información de contacto, por favor escriba sus iniciales aquí: ______. Esta información se ingresará en una hoja de cálculo de Excel que está completamente separada de cualquier cosa relacionada con este estudio de investigación y mantenida por un período de cinco años en una carpeta de acceso restringido en Box.com. Puede ponerse en contacto con el Investigador Principal en cualquier momento para quitar su información de contacto de esta lista.

Revisión del IRB

La Junta de Revisión Institucional (IRB) de Utah State University para la protección de humanos participantes en investigaciones ha revisado y aprobado este estudio. Si tiene preguntas sobre el estudio de investigación en si, por favor contacte al Investigador Principal al 801-518-3193 o steven camicia@usu.edu. Si tiene preguntas sobre sus derechos o si sencillamente desea hablar con alguien sobre sus preguntas o dudas quien no sea parte del equipo de investigación, por favor comuníquese con el Director de la IRB al (435) 797-0567 o inb@usu.edu

Por fayor _{sy} coloque una firma electrónica		Роб fayora coloque una firma electrónica	
Steven Gamicia		William Eric Strong	
Investigador Principal		Investigador Estudiantil	
801-518-3193; steven.camicia@usu.edu	`	208-243-4143; eric.strong@aggiemail.usu.edu	

Consentimiento Informado

Al firmar lo de abajo, usted da su consentimiento para participar en este estudio. Usted indica que entiende los riesgos y beneficios de la participación, y que sabe lo que se le pedirá que haga. Usted también acepta que ha hecho cualquier pregunta que tenga, y que tiene claro cómo detener su participación en el estudio si decide hacerlo. Por favor, asegúrese de conservar una copia de este formulario para sus registros.

	V		
Firma del Participante	N	Nombre del Participante Imprimido	Fecha
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INSTITUTIONAL REVIEW BOARD v.10 9.1.2016 Número de teléfono Correo electrónico donde podemos ponernos en contacto con usted, si es necesario School of Education and Leadership | 435-797-1473 | 2805 Old Main Hill | Logan, UT 84322

Special Education Processes Survey

Q1. In your opinion, what are the most important qualify (You may indicate more than one response).	ality of life issues facing your son/daughter today?
 □ There are no important issues □ Adequate yearly academic growth □ Adequate socialization □ Having friends □ Being Labeled □ Being teased □ being bullied / cyber-bullied □ Moving to the next grade □ Learning to decode text in written language 	□ Learning to read □ Learning skills necessary to get a job □ Learning math skills □ Learning writing skills □ Learning to communicate with peers □ Learning to communicate with adults □ Being understood □ Being meaningfully employed □ Other
Q2. In your opinion, to achieve the items in question things that need to be done for your child right now?	
 □ There are no important issues □ Do nothing at this time □ Wait and see □ Find out how my son/daughter's school might help □ Call my child's teacher □ Call my child's principal □ Having him/her evaluated □ Identify his/her strengths and weaknesses □ Meet with professionals at my child's school to talk about my concerns 	 □ Get a diagnosis for my son/daughter so he/she can get help □ Make a plan for son/daughter with his/her school □ Seek services necessary for my son/daughter outside of the school □ See my son/daughter's family practitioner for help □ Other □ Not Applicable □ Don't know □ Prefer not to answer
Q3. Now I have some questions about the Special Edward would you say getting a child into Special Education not a problem in the state you are currently living in a	services is a major problem, a minor problem, or
O Major problem O Minor problem O Don't know	
Q4. In general, would you say getting <u>your</u> child into minor problem, or not a problem at all in your child's	
O Major problem O Minor problem O Don't know	
Q5. What do you think of when you brought up conc may provide more than one response).	erns about your child to your child's teacher? (You
 □ Helpful □ Not helpful □ Encouragin □ Useful □ Fruitful □ Not Useful □ Confusing □ Clear □ Overwhelming □ Able to spe 	Exactly as expected time Informed Uninformed

Q6. What do you think of when you think about the way your child's teacher responded to your concerns? (You may provide more than one response).								
Useful Not Useful		Encouraging Fruitful A waste of time Productive		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know				
Q7. What do you think of when you think about the way special education staff addressed your concerns? (You may provide more than one response).								
Useful Not Useful Confusing Clear Overwhelming		Productive Not productive Able to speak my mind		Don't know				
What do you think of when you vide more than one response).	thin	ık of your child's Special Educa	tion	evaluations? (You may				
ε		I		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know				
What do you think of when you aluation Review meeting? (You r				staff talked to you at				
Helpful Not helpful Useful Not Useful Confusing Clear Overwhelming		Inspiring Encouraging Fruitful A waste of time Productive Not productive Able to speak my mind		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know				
O. What do you think of when yo daughter at the Evaluation Revi-Helpful Not helpful Useful Not Useful Confusing Clear Overwhelming		neeting? (You may provide more Inspiring Encouraging Fruitful A waste of time						

resp	meeting where goals and a plan of implementation were developed? (You may provide more than one response). *(IF THIS IS THE SAME MEETING AS THE EVALUATION MEETING THEN CHECK SAME AND SKIP TO QUESTION 14)							
	Useful Not Useful Confusing Clear		Inspiring Encouraging Fruitful A waste of time Productive Not productive Able to speak my mind		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know			
	2. What do you think of when yo ividual Education Plan meeting?							
	Helpful Not helpful Useful Not Useful Confusing Clear Overwhelming		Inspiring Encouraging Fruitful A waste of time Productive Not productive Able to speak my mind		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know			
	3. What do you think of when yo daughter at the Individual Educa							
	Helpful Not helpful Useful Not Useful Confusing Clear Overwhelming		Fruitful A waste of time Productive Not productive		Didn't know what to say Didn't know what to expect Exactly as expected Informed Uninformed Other Don't know			
	4. In your opinion what do you the vices? (You may provide more the			l's S	pecial Education			
	Helpful Not helpful Useful Not Useful Confusing		Not confusing Overwhelming Inspiring Encouraging Fruitful		A waste of time Productive Unproductive Other Don't know			
Q1: O	5. Your child's special education Strongly agree Somewhat agree		vices affect your child's quality Neither agree nor disagree	of li O O	fe at his/her school? Somewhat disagree Strongly disagree			
Q10 O	Q16. Your child's special education services affect your child's quality of life at home? O Strongly agree O Neither agree nor disagree O Somewhat disagree							

Q11. What do you think of when you think of your child's Special Education Individual Education Plan

Q1' O	7. Your child's special education Strongly agree Somewhat agree		vices affect your child's quality Neither agree nor disagree		fe in his/her community? Somewhat disagree Strongly disagree
	8. Your child's special education currently reside?	serv	vices affect your child's quality	of li	fe in the state within which
0	Strongly agree	O	Neither agree nor disagree	O C	Somewhat disagree Strongly disagree
Q19	9. Special education affects your	chile	d's quality of life.		
0		0	Neither agree nor disagree	0	Somewhat disagree Strongly disagree
Q20	O. Having a child who needs spec				
O O	Strongly agree Somewhat agree	0	Neither agree nor disagree	O	Somewhat disagree Strongly disagree
Q2	1. Seeing a child with special nee	eds i	n my child's school does NOT u	ıpset	most people.
O O		0	Neither agree nor disagree	O O	Somewhat disagree Strongly disagree
Q22	2. Seeing a child with special nee	ds i	n your child's school DOES ups	et yo	ou personally.
O	Strongly agree Somewhat agree	O	Neither agree nor disagree	O	Somewhat disagree Strongly disagree
Q2:	3. Special education programs co	st ta	xpayers money.		
O O	0,00	O	Neither agree nor disagree	O C	Somewhat disagree Strongly disagree
Q24	4. Special education programs ar	e ex	pensive for school districts to op	erat	e.
0	Strongly agree		Neither agree nor disagree	O C	
Q2:	5. School districts should spend 1	none	ey on things other than special e	duca	ation programs.
0	Strongly agree		Neither agree nor disagree	O	Somewhat disagree Strongly disagree
020	6. The special education process	need	ls to change.		
ò o	Strongly agree Somewhat agree		Neither agree nor disagree		Somewhat disagree Strongly disagree
02	7. More children should be allow	ed to	o receive special education servi	ices.	
0			Neither agree nor disagree	O O	Somewhat disagree Strongly disagree
028	8. Fewer children should be allow	ved 1	to receive special education serv	vices	
0	~ .	O	Neither agree nor disagree))	Somewhat disagree Strongly disagree
	9. I felt like I had the same powe son/daughter's special education			cial e	education team members in
O	Strongly agree Somewhat agree		Neither agree nor disagree	O O	Somewhat disagree Strongly disagree

Q30	Q30. I felt like a member of the special education team who had an equal voice.						
O	~ · ·)	Neither agree nor	r			Somewhat disagree
0	Somewhat agree				()	Strongly disagree
03	1. I did most of the talking at my so	nn/	daughter's special	1	education me	etin	σ
			Neither agree nor				Somewhat disagree
	Somewhat agree		Tyordior agree nor				Strongly disagree
_	Zome what agree					_	Subligity disagree
Q32	2. I did most of the listening at my	so	n/daughter's speci	ia	al education m	ieet	ing.
O	\mathcal{E} \mathcal{F})	Neither agree nor	r	disagree	\mathbf{C}	Somewhat disagree
O	Somewhat agree				(\mathbf{C}	Strongly disagree
020			1		1.11.	,	'
	 I had an equal voice and did an ecial education meeting. 	qu	ial amount of talki	ın	ig and listenin	ig d	uring my son/daughter's
	Strongly agree)	Neither agree nor	r	disagree (\mathbf{O}	Somewhat disagree
	Somewhat agree		retifier agree nor				Strongly disagree
	4. Great! You are just about through	h.	The final question	าร			
	this investigator analyze the resul						
	you consider your place of residen			o	r urban area, a	a su	burban area, a small city or
	n, a rural area on a farm or ranch,	or	a rural area NOT o	0	n a farm or ra	nch	?
\mathbf{O}	Large city or urban area		O		Rural area NO)TC	on a farm or ranch
	Suburban area				Don't know		
	Small city or town		•		Refused		
	Rural area on a farm or ranch						
Q3:	5. Including yourself, how many pe	eop	ole do you have liv	Vİ	ing in your ho	use	hold?
03/	6. How many children, age 17 or yo	011	ngar do vou hava	1	iving in your	hou	usahold?
QS	5. How many children, age 17 of yo	Ju	inger, do you nave	1	iving in your	nou	ischold:
Q3′	7. How many children, ages 21 or y	you	ınger, do you have	e	that have a di	agn	osed disability?
Q38	3. How many children, ages 21 or y	yoı	inger, are currently	y	on an Individ	lual	Education Plan?
Q39	9. How many children, ages 0 to 3;	0 a	are on an Individua	a.	l Family Servi	ice	Plan?
040). What is the current classification		f vour child/childr	۰,	on with a dicah	silit	v? Child 1.
_	autism	ı O.	O Sour chind/chindre		orthopedic im		
	deaf-blindness		Ö		other health in		
	deafness		Ö		specific learni		
	emotional disturbance		•				ge impairment
\mathbf{O}	visual impairment		O		traumatic brai		
\mathbf{O}	hearing impairment		•		al impairment	t (in	cluding blindness)
O	intellectual disability						
O	multiple disabilities						
04	What is the second classification		C 1-:1.4/-1-:1.4		:41	. :1:4	0 CL:14 0.
Q4.	 What is the current classification Not Applicable 	1 ().	your child/childre		multiple disat		
o	autism		Ö		orthopedic im		
0	deaf-blindness		Ö		other health in		
Ö	deafness		Ö		specific learni		
ŏ			Ö				ge impairment
Ō			Ö		traumatic brai		
O	intellectual disability		O				at (including blindness)
	•		O		Development		

Cor	ndition: Not Applicable Is Selected. Skip To: What	is th	ne highest level of education?				
042	2. What is the current classification of your child/cl	hildr	en with a disability? Child 3:				
O Not Applicable O multiple disabilities							
0	* *	\mathbf{O}	orthopedic impairment				
0	deaf-blindness	\mathbf{O}	other health impairment				
Ō			specific learning disability				
0	emotional disturbance		speech or language impairment				
	hearing impairment		traumatic brain injury				
\mathbf{O}			visual impairment (including blindness)				
	·		Developmental Delay				
Cor	ndition: Not Applicable Is Selected. Skip To: What	is th	ne highest level of education?				
043	3. What is the current classification of your child/cl	hildr	en with a disability? Child 4:				
Ò			multiple disabilities				
	autism		orthopedic impairment				
0	deaf-blindness		other health impairment				
0	deafness	0	specific learning disability				
0	emotional disturbance	0	speech or language impairment				
\mathbf{O}	hearing impairment	\mathbf{O}	traumatic brain injury				
\mathbf{O}	intellectual disability	\mathbf{O}	visual impairment (including blindness)				
		0	Developmental Delay				
Cor	ndition: Not Applicable Is Selected. Skip To: What	is th	ne highest level of education?				
ΩA	4. What is the current classification of your child/cl	hildr	en with a disability? Child 5:				
O		O	multiple disabilities				
	autism	o	orthopedic impairment				
	deaf-blindness		other health impairment				
	deafness		specific learning disability				
	emotional disturbance		speech or language impairment				
	hearing impairment		traumatic brain injury				
0	intellectual disability		visual impairment (including blindness)				
	·		Developmental Delay				
04	5. What is the highest level of education you have	comi	oleted?				
	Less than high school	O	4-year degree				
	High school graduate	O	Professional degree				
O	~	O	Doctorate				
\mathbf{C}	2-year degree						
04	6. What is your employment status?						
O.	Employed full time	O	Retired				
ŏ	Employed part-time	Õ	Student				
Ö		ŏ	Disabled				
Ō	Unemployed not looking for work	-					

Condition: Unemployed looking for work Is Selected. Skip To: What is your current occupation?

000000	7. What is your current occupation Agriculture / farming Construction / carpentry / plumb / craftsman Landscaping Manufacturing / factory / indust Education Government services (police, fit worker, etc.) Mechanical / machine servicing automobile mechanic) Computer / technical / electronic	rash, postal	00000	Transportation Retail / whole Finance / insu	n / s sal ran ltir	e sales ace / real estate ag / data analysis	
Q48	3. Which of these categories best	des	cribes your to	tal ho	ousehold incom	ne t	pefore taxes last year? (Read
list;	choose only one.)						
O	Less than \$10,000	\mathbf{O}	\$40,000 - \$4	9,99	9 (O	\$80,000 - \$89,999
\mathbf{O}	\$10,000 - \$19,999	\mathbf{O}	\$50,000 - \$5	9,99	9 ()	\$90,000 - \$99,999
\mathbf{O}	\$20,000 - \$29,999	\mathbf{O}	\$60,000 - \$6	9,99	9 ()	\$100,000 - \$149,999
0	\$30,000 - \$39,999	O	\$70,000 - \$7	9,99	9 ()	More than \$150,000
Q49	9. What best describes your age?						
O	Under 18	\mathbf{O}	35 - 44)	65 - 74
O	18 - 24	\mathbf{O}	45 - 54)	75 - 84
0	25 - 34	O	55 - 64)	85 or older
\square N). What is your gender? Male □ Female I. What races or ethnic backgrou	nd d	o vou conside	er voi	urself? (Check	all	that apply)
	White or Caucasian	114 4	o you conside				or other Pacific Islander
	Black or African-American				Vietnamese		
	Hispanic or Latino				Middle Easter	n	
	(includes Mexican, Central Am	erica	an, etc.)		African (NOT	' A:	frican-American)
	Native American or Alaskan na						m India, Pakistan,
	Korean				Bangladesh, e		
	Japanese				Other		
	Chinese				Don't know		
	Filipino				Refused		
Q52	2. Does your child go to:						
\mathbf{O}	A Public School						
\mathbf{O}	A Charter School						
O	A Private School						
Q53	3. What is your zip code?						

Potential Interview Questions

Background and History:

- 1. Tell me about yourself, your family, and about ______ so that I can get know all of you better. (Do for a living? Education level? How many in the family? Child?)
- 2. Tell me the background as to why you considered participating in this research study.
- 3. Thinking about ______, when did you first become concerned with his/her development? Was it something you were aware of from early on or was it brought up by the school? Was his/her problem diagnosed by the school or were doctors involved? (Tell me as much as you willing to share):

I would like to focus for a few minutes on the referral process.

- 4. Who was having concerns and what were the concerns?
- 5. Tell me about when the school first contacted you about learning/educational concerns of your child? (At that time, how did that contact make you feel?)
- 6. In thinking about those contacts with special education staff, who contacted you (if you recall) and how did that initial contact come across? (Were you surprised, relieved? Describe your reaction and feelings following?) Did you follow up with school staff regarding these feelings?

Now, I would like to focus on the evaluation process.

7. Tell me from your viewpoint what took place. Do you recall how long the process took? Was it reasonable? Was there on-going contact during this process?

I would like to focus on the evaluation review and first IEP meeting you had for your child.

- 8. If you can, please paint a picture for me of that meeting with your words. (Prompt for who was in the room).
- 9. True or False: I felt like I had the same power (voice, say, authority) as other members in the room? (Explain your answer).
- 10. True or False: I felt like a member of the team who had an equal voice? (Explain your answer).
- 11. I did: A) most of the talking at this meeting; B) Most of the listening at this meeting; C) I had an equal voice and did an equal amount of talking and listening (Explain your answer)
- 12. When the school personnel "broke the news" about my son/daughter's impairment(s), I felt ______. (Explain your answer)
- 13. Did the other team members, when they talked about your child, emphasize his/her strengths or his/her weaknesses? (Explain your answer)
- 14. True or False: I felt confident about the decisions being made regarding my child as I had an equal voice in the decision making? (Explain your answer).
- 15. True or False: I did not feel like any of the educational decisions regarding impairment was predetermined? (Explain your answer).
- 16. True or False: I understood everything that took place at that meeting; staff went out of their way to explain everything? (Explain your answer).

- 17. Tell me about the IEP. Did you participate or have input in developing your child's educational goals? Were the goals pre-determined?
- 18. How did you feel about the amount of time your child would receive (or receives) for special education services?
- 19. Do you currently agree with the special education plan that has been developed for your child? (Can you explain? What changes if any? If there are changes that you would like to see, do you feel comfortable asking for those changes?)

Other Questions

- 20. How frequently does a special education staff member contact you regarding your child and his/her progress? (Is this adequate? If not, how frequently do you feel you should be contacted?)
- 21. If you had to describe the special education process in a single word, what would it be? Explain your answer.
- 22. Do you believe the special education program is helping your child? Why or why not?
- 23. If you could wave a magic wand, what would you change regarding the special education process?
- 24. Is there anything I did not cover, that you would like to address concerning the special education process?

Statement of Transcription Security



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CURRICULUM VITA

WILLIAM ERIC STRONG Utah State University (208) 243-4143 eric.strong@aggiemail.usu.edu

EDUCATION

Utah State University, Logan, UT, 2017 School of Teacher Education and Leadership

Ph.D. Curriculum and Instruction

Dissertation: A Grounded Case Study of Parental Perceptions Surrounding Formalized Special Education Process

Advisor: Steven P. Camicia, Ph.D.

Utah State University, Logan, UT, 2010 School of Teacher Education and Leadership Administrative-Supervisory Credential

Utah State University, Logan, UT,1990 Communicative Disorders

M.S. Speech-Language Pathology

Thesis: A Review of Informal Measures Used to Assess Oral-Syntactic Ability in Normal and Language-Impaired School-Aged Children

Advisor: Sonia Manuel-Dupont, Ph.D.

University of Utah, Salt Lake City, UT, 1988 Humanities, Arts, and Social Sciences B.A. Linguistics, French Minor

HONORS

Nominated for Dissertation of the year, *Utah State University* (2018).

PROJECTS

Co-Investigator with Steven Camicia, Ph.D. - A Grounded Case Study of Parental Perceptions Surrounding Formalized Special Education Processes (2016-2017).

Improving Student Safety for K-8 Students While Increasing Time Spent in Class for Kindergarteners in Preston Joint School District # 201 (Action Research, 2010).

Co-Investigator with Truman Coggins, Ph.D. - How Children Use Language to Solve Social Problems (Completed Pre-Dissertation Project, 2004).

A Review of Informal Measures Used to Assess Oral-Syntactic Ability in Normal and Language-Impaired School-Aged Children (Master's Thesis, 1990).

BOOK CHAPTERS

Dinno, N., Hay, A., Strong, W.E., Coggins, T., Wendel, S., & Cook, D. (2000). *A child with Fragile X Syndrome*. In M. Guralnick (Ed.), Interdisciplinary clinical assessment of young children with developmental disabilities.

PUBLICATIONS

Strong, W.E. (Winter, 2000). *Fetal Alcohol Syndrome*. News Exchange. American Association of Home-Based Early Interventionists. 5(1), 1-5.

INVITED PRESENTATIONS

(October 2009). Strong, W.E. and Strong, E.J. *Aspects of Autism and Related Neurodevelopmental Disorders*. Invited presentation for the Autism Spectrum Support group of Options for Independence--Northern Utah Center for Independent Living at Logan Regional Hospital, Logan, UT.

(March 2003). Strong, W.E. What Clinicians Need to Understand Regarding the Measurement and Treatment of Social-Communication Skills in School-Aged Children. Invited presentation to Snohomish County, Washington, Speech-Language Pathologists, Everett, WA.

(May 2002). Strong, W.E. *Aspects of Asperger's Syndrome*. Invited presented to Cascade View Elementary School teachers, parents, and support staff, Snohomish, WA.

(January 2001). Strong, W.E. *Aspects of Asperger's Syndrome*. Invited presentation to Snohomish School District Speech and Language Pathologists, Snohomish, WA.

(May 1992). Strong, W.E. *Communication Milestones and Promoting Communication Development in the Home*. Invited presentation to parents within the Chinook Health Unit region, Pincher Creek, Alberta, Canada.

PRESENTATIONS

(October 2017). Strong, W.E. *Grounded Case Study of Parental Perceptions Surrounding Formalized Special Education Processes*. Completed Dissertation presented in Partial fulfillment of the requirements of the degree Doctor of Philosophy in Education with Specialization in Curriculum and Instruction, Administrative Emphasis, Utah State University, Logan, UT.

(April 2017). Strong, W.E. A Grounded Case Study of Parental Perceptions Surrounding Formalized Special Education Processes. A presentation completed in Partial fulfillment of the requirements of the degree Doctor of Philosophy in Education with Specialization in Curriculum and Instruction, Administrative Emphasis, at the Graduate Research Symposium, Utah State University, Logan, UT.

(January 2017). Strong, W.E. A Critical Case Study of Parental Perceptions Surrounding Formalized Special Education Processes. Dissertation Proposal presented in Partial fulfillment of the requirements of the degree Doctor of Philosophy in Education with Specialization in Curriculum and Instruction, Administrative Emphasis, Utah State University, Logan, UT.

(May 2004, 2005, 2006). Strong, W.E. *Communication Milestones and Promoting Communication Development in the Home*. Presentation to parents and professionals, Special Children's Clinic, Las Vegas Nevada.

COURSES TAUGHT

(Spring Semester, 1999). Speech-and-Hearing Sciences 304, *Developmental Aspects of Communication* at the University of Washington.

Developed Course Readers 1, 2, 3—Speech-and-Hearing Sciences 304, *Developmental Aspects of Communication*, University of Washington

DEVELOPED PARENT TRAINING MANUALS

Strong, W.E. (2009). Direct Stuttering Treatment Techniques.

Strong, W.E. (1993, 1994, 1995, 1996). Monthly home program manuals targeting thematic activities that promote language stimulation and communication development.

Strong, W.E., & Henderson, R. (1991, 1995). *Home Activities for Children Birth-to-Three Years (A parent's guide)*.

DEVELOPED STUDENT TRAINING MANUALS

Strong, W. E. (2005). Strong Practice of Idiom Tasks

Strong, W.E. (2001). Strong Idiom Practice

DATA COLLECTION AND ANALYSIS

Twenty-Seven years-experience collecting and analyzing data

QUANTITATIVE DATA AND ANALYSIS EXPERIENCE

Daily work as a Speech-Language Pathologist collecting, analyzing, interpreting, and summarizing quantitative information for parents and team members

Project: (2003) How Children Use Language to Solve Social Problems, Pre-Dissertation Project, University of Washington

Project: (1999) Measuring Reasoning Skills in School-Age Children: Stability of Student Responses—A Preliminary Investigation, University of Washington

Project (1998) Narrative production of children with Fetal Alcohol Syndrome, Single Subject Design, University of Washington

Master's Thesis: Strong, W.E. (1990). A Review of Informal Measures Used to Assess Oral-Syntactic Ability in Normal and Language-Impaired School-Aged Children (Master's Thesis). A project completed in partial fulfillment of the degree Master of Science in Communicative Disorders, Speech-Language Pathology

Evaluation Courses:

EDUC 6010 Program Evaluation

Research Courses:

EDUC 6075 Education Research

Statistical Series:

EDUC 6600, Research Design and Analysis I EDUC 7610, Research Design and Analysis II

QUALITATIVE DATA AND ANALYSIS EXPERIENCE

Dissertation Project: Strong, W.E. (2017). A Grounded Case Study of Parental Perceptions Surrounding Formalized Special Education

Processes (Oct. 30, 2017). A Dissertation completed in partial fulfillment for the degree Doctor of Education

Project: Strong, W. E. (2013). *Perceptions of the Special Education Process, Interviews with Parents*, Project for Qualitative II, EDUC 7780

Research Courses:

EDUC 6770, Qualitative Research I EDUC 7780, Qualitative Research II

CERTIFICATION

- UT License, Level III: CACTUS ID: 62774, Administrative/Supervisory Credential (K-12) (2022)
- UT License, Level III: CACTUS ID: 62774, Comm. Disorders-Speech-Language Path K-12+) (2022)
- Certificate of Clinical Competence in Speech-Language Pathology, No. 01094798: (2017)

EXPERIENCE

- 2016—2017 Part-Time Speech-Language Pathologist for EBS Health Care, Albuquerque Public Schools and Rio Rancho Public School District while completing data collection for PhD dissertation project
- 2014—2016 2-year Speech-Language Pathologist for Nebo School District, Utah. SLP at Mount Loafer Elementary School, Salem, UT (Pre-K to Grade 6) Supervisor for Clinical Fellowship Year (CFY) candidate and Speech-Language Technician
- 2006-2014 8--year Lead Speech-Language Pathologist contract with Preston School District, Idaho
- 2006-2014 Lead Speech-Language Pathologist
- 2009-2010 SLP, administrative intern
- 1999-2006 6-year Speech-Language Pathologist contract with Snohomish School District #201, Washington, serving preschool, elementary, and middle-school students; primary caseload: children with neuro-behavioral disorders

1996-1999 Assessed neuro-atypical children at a nationally recognized site, Center on Human Development and Disability (CHDD), University of Washington, Seattle, Washington

Supervised 1st- and 2nd-year Master's level students completing childassessment and treatment practicums (CHDD and Speech and Hearing Sciences Department, University of Washington

Served 9 months on the Fetal Alcohol Syndrome Diagnostic and Prevention Network Clinic, CHDD

Taught Speech and Hearing Sciences 304, Developmental Aspects of Communication, at the University of Washington

1993-1996 Provided service to infants and toddlers; provided daily parent training, counseling, program planning monthly parent-training sessions, Special Children's Clinic (SCC), Las Vegas, Nevada

Member of the Southern Nevada Cranio-Facial Clinic at SCC

Member of the Southern Nevada Neonatal Intensive Care Unit Clinic, Sunrise Children's Hospital, Las Vegas Nevada

SUPERVISORY WORK

2013-2015 Nebo School District, Utah

- Supervisor for one speech-language technician
- Supervisor for a Clinical Fellow completing a Clinical Fellowship Year (CFY) (2014-2015)

2006-2013 Preston School District, Idaho

- Supervisor for one to two paraprofessionals and one speechlanguage technician
- Clinical Supervisor for USU graduate students completing practicums (2006-2013)
- Supervisor for a Clinical Fellow competing a CFY (2008-2009)

2000-2006 Snohomish School District, Washington

- Supervisor for one paraprofessional and one speech-language technician
- Supervisor for a Clinical Fellow completing a Clinical Fellowship Year (2001-2002)

1998-1999 Department of Speech and Hearing Sciences, University of

Washington

•

Clinical Supervisor for first and second-year graduate-level students completing treatment practicums within the Speech-and Hearing Sciences Department, University of Washington, Seattle, Washington, in the Speech and Hearing Clinic, a nationally ranked outpatient center providing clinical serves, clinical education, and operates as a research facility.

1996-1998 Washington

Center on Human Development and Disability, University of

Clinical Supervisor for first-and second-year graduate-level students completing assessment practicums at the Center on Human Development and Disability, University of Washington, Seattle, Washington, in the Clinical Training Unit, an interdisciplinary program that provides training, research, and exemplary services in the assessment and treatment of children with or at risk for developmental disabilities, using a family-centered, community-based, culturally competent approach.

1992-1996 Special Children's Clinic, Las Vegas, Nevada

- Supervisor for four paraprofessionals assisting in providing language-based group therapy services to children aged birth to three
- Supervisor for a Clinical Fellow completing a CFY (1994-1995)

1991-1992 Chinook Health Unit, Alberta, Canada

• Supervisor for a Clinical Fellow competing a CFY

PROFESSIONAL AFFILIATIONS

American-Speech-Language-Hearing Association (1990-2017) Utah Speech-Language-Hearing Association (2013-2017) Idaho Speech-Language-Hearing Association (2008-2013) Washington Speech-Language Hearing Association (2001-2006)