The Lived Experience of Parents Experiencing Poverty While Navigating The Special Education Process

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Dedication

This dissertation is dedicated to all the first in their family to break a barrier, to everyone who was told they couldn't, and to those who dared to try when everyone around them told them they couldn't.

"*Illegitimum non carborundum"*

- Harvard University fight song

Acknowledgments

My humblest gratitude goes out to those who have supported me throughout this journey. As the first in my family to earn an advanced degree, I know that without the help of the many, many supporters around me, I'm not sure I would have seen my early dream turn into an accomplished goal. To my husband, Michael, thank you for your patience, constant encouragement and the gift of time and space to finish. To HC, my constant writing companion, thank you for always being there to see me through. To the faculty and staff of The George Washington University, what an amazing team I had behind me. Your commitment to seeing me better than I saw myself at times in this process is a gift where thank you simply is not enough. To Dr. Tuckwiller, and Dr. Rice, thank you for pushing me into the uncomfortable, for pushing me to seek questions to harder questions. It is because of you that I have had pedological shifts in not only my teaching practice, but also in my appreciation of my fellow human beings.

Finally, to my participants. Thank you for your openness. Know that you have been heard and that I will use everything you have taught me to champion for your authentic voices to be strengthened, respected and included in our joint ventures in the world of academia.

Abstract of Dissertation

The Lived Experience of Parents Experiencing Poverty While Navigating The Special Education Process

This research study was situated in the policies of the Individuals with Disabilities Act (IDEA) and motivated by the different ways parents from different socioeconomic groups navigate special education. IDEA requires parents to make informed decisions about their child's special education needs. It assumes access to information is the same as having competency to navigate and utilize that information. In schools, much of the information in special education is provided in writing. The Parents Rights and Procedures manuals that describe parents' rights throughout the special education process are often written at a high school and greater reading level. Parents of low socio economic status (SES) communities tend to achieve lower levels of education than those not of low SES communities. If parents of a child with a disability from low SES communities are unable to access the written information to make informed decisions about their child's needs, how do they access and utilize information in their decision making process? How is their decision making experience impacted by the information they do/do not have when making decisions for their child's special education needs?

This phenomenological study examined the lived experience of nine parents from low socio economic communities as they made educational decisions about their child(ren) with special needs. Each parent qualified for free and reduced lunch and had a child that was currently receiving special education services. The study utilized a hermeneutic phenomenological approach to identify both the details of the parents lived experiences

and how each made sense of their experience. Through the lens of a Heuristics and Biases Framework, data was analyzed to identify key themes about the parent's lived experiences.

Findings for this study were organized into themes that included the importance of communication, establishing positive relationships, the emotional toll on parents and difficulty finding information. Findings highlighted the significance of interactions in socio academic settings as well as how parents use the information they have to make decisions. The findings of this study add dimension to our understanding of this phenomenon and further develop the literature on the experiences and expectations put upon parents of children with a disability from low socio economic communities. The findings also have implications for further research, institutional attitudes and policies, as well as curricular and pedagogical approaches.

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CHAPTER ONE: INTRODUCTION

Overview

In 2014, 6,464,096 children ages 3 to 21 years received special education services in the United States (NCES, 2015a). Parent participation in the special education process is mandated by the Individual with Disabilities Education Act (IDEA, 2004). Parents are expected to be active participants in the processes of assessing, planning, and developing their child's eligibility determination for special education services and developing their child's Individual Education Plan (IEP) (IDEA, 2004). For parents to make informed decisions about their child's education, they must be familiar with the various complexities of the law and their rights under the law. Ensuring that parents are well-informed and involved in their child's education is at the heart of special education policy. However, due to the volume of information they receive, and the legal and technical terminology, many parents of students with disabilities find understanding special education materials and regulations daunting (Burke, 2013). This challenge is compounded when parents are undereducated or their reading levels do not match their educational levels (Nagaro & Stein, 2016). Further compounding these challenges are the effects of poverty.

Families living in poverty from one generation to the next, or situationally for an extended period of time (e.g., multiple years), tend not only to remain poor, but also tend to achieve low levels of formal education generation after generation (Beegle, 2003). For parents with low education rates, low literacy and living in poverty, remaining informed about special education law may be highly desired but low among their competing priorities (Mandic et al., 2012). Although there is strong evidence that

parental involvement is an important protective factor against adverse educational and social outcomes later in life for children with disabilities, research on parental involvement indicates that a considerable number of low income, nonwhite parents of children with disabilities report a discrepancy between their actual and desired levels of parental involvement in the IEP process (Mandic et al., 2012).

Statement of the Problem

Parental participation in the special education process is mandated by the Individuals with Disabilities Education Act (IDEA, 2004). Parents are expected to be active participants in the assessment, planning, and development of their child's Individual Education Plan (IEP). Current special education policy assumes equitable skills by all parents. It assumes literacy, the understanding of the continuum of services, the understanding of the special education process, and a parent's ability to dispute findings and negotiate a more appropriate outcome for their child. Current policy assumes that "*access to"* is the same as "*competency to navigate"* the special education process and that such skill is the same skill for every parent. For this study, access will be defined as the ability to make contact with, reach or interact with an object.

Decision-making events in the special education process that must include a parent by law include the identification of a disability, programmatic planning and implementation of services, and assessment (IDEA, 2004). For parents to become involved, they need to be familiar with the various complexities of special education law, as well as their rights, to assist in making informed decisions about their child's education. Research on parental participation in the special education process focuses

on establishing collaborative relationships, increasing parental involvement in schools, the benefits of parental involvement on student performance, and ways to predict parental involvement. However, there is limited information on how parents in low socioeconomic communities make decisions about their child's educational needs and the barriers they face when making these decisions.

Currently, there is a gap in the literature regarding how parents in low SES communities who have a child with a disability make decisions about their child's special education needs. According to the 2014 U.S. census report, it was estimated that approximately 15 million children under the age of 18 and their families lived with incomes below the federal poverty threshold (DeNavas-Walt & Proctor, 2015). Children with disabilities are among the poorest and most vulnerable members of U.S. society (Groce et al., 2011). Children living in economic disadvantage have the highest rate of disability (Houtrow et al., 2014). However, although the relationship between disability and living in poverty is well researched, how parents in low SES communities make decisions about their child's special education needs has not been examined (Groce et al., 2011).

A review of the literature on parental participation in the special education process focuses on the experiences of specific demographic groups including: culturally and linguistically diverse parents (Stanley, 2015; Waitoller & Super, 2017), immigrant parents of students with disabilities (Burke, 2017; Kim & Kim, 2017; Larios, 2012) parents with low education levels and those of low SES communities (FEDC, 2012; Thurston & Navarrete, 2011; Trainor, 2010b), and practices to improve parent-teacher partnerships (Al-Dababneh, 2018; Cobb, 2014; Goldman & Burke, 2017). Although

there is research on how parents feel about the process, there is limited research on how parents participate in decision-making throughout the eligibility and educational planning processes. Furthermore, there is a dearth of research on the decision-making processes and experiences of parents of low SES communities that have children with a disability participating in the special education process.

This study explored how parents in low SES communities gathered information to make educational decisions about their child's special education needs. This study aimed to add to the research on parent involvement in special education by examining the experiences of parents of children with disabilities in low SES communities and the barriers they faced when advocating for the educational needs of their children.

Purpose and Research Questions

The purpose of this phenomenological study was to understand the decision-making experiences of parents from low SES communities regarding their children's special education needs. The study sought to answer the following about parents of children with disabilities from low SES communities. The following research questions guided the inquiry:

1. How do parents of low SES communities experience their child's disability?
2. What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?
3. How do parents from low SES communities interpret their rights and responsibilities in the educational process?

4. How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?

This study utilized individual interviews (Creswell, 2007) designed to explore parent's experiences in relation to the special education process and where and with whom they seek out assistance when uncertain about what to do during the process.

Statement of Potential Significance

There is a bi-directional relationship that exists between poverty and disability: poverty, through exposure to environmental hazards, can lead to disability; and disability, and its associated increased financial burdens, can lead to poverty (Emerson, 2007; Parish et al., 2008). It is important to address the lack of research on how parents of children with disabilities in low SES communities not only gather information about special education, but how they use this information to make decisions about their child's educational needs.

There is an assumption by education professionals that parents understand the written information that is provided to them, as well as terms commonly used in education (Fish, 2006; Fish 2008; Fitzgerald & Watkins, 2006; Skinner, 1991). Due to these assumptions, educators fail to check for understanding or explain information and processes clearly to parents (FEDC, 2012; Lo, 2008; Klinger& Harry, 2006; Pang, 2011). Findings from this study would be useful to school personnel as they develop programs that encourage active parental participation throughout the special education process. The study aimed to contribute to a deeper understanding of how parents, regardless of their economic or educational status, can be supported in making informed decisions about the

special education needs of their child. The findings may also inform current policies on creating accessible written communication that is intended to inform parents of their rights, but remains inaccessible due to high readability levels.

Theoretical Framework

Heuristics and Biases Framework

The phenomena of the parental decision-making process was examined through the lens of the Heuristics and Biases Framework (Kahneman & Tversky, 1973). This framework provided assumptions about how individuals both received and processed information to make decisions under circumstances of uncertainty, especially in the face of ambiguous, complicated, and/or incomplete information (Chaudry et al., 2010; Thaler & Sunstein, 2008; Tversky & Kahneman, 1974).

In this framework, construals were how individuals perceived, comprehended and interpreted the world around them (Bruner, 1957; Griffin & Ross, 1991; Nisbett et al., 1973). The heuristic process itself is defined as strategies an individual uses to make a decision about something with which they are unfamiliar, that is complex, or when the individual has little practice in making such a decision (Chaudry et al., 2010). This study applied both construals and the heuristic process to explore how parents used information to make decisions about their child's educational needs. Research on poverty, access to resources, and the readability of documents was discussed to determine how each informed the decision-making processes of parents of low SES communities regarding their child receiving special education services.

Summary of Methodology

Epistemology

Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation (van Manen, 2007). They are powerful for understanding subjective experiences, gaining insights into people's motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom (van Manen, 2007).

Phenomenological methodologies were uniquely suited for this study to illuminate the meaning of an experience, and to identify a phenomena through how it is perceived by the individuals in the situation. As phenomenology is concerned with the study of a lived experience from the perspective of the individual, phenomenological methodologies are useful in studies that are aimed at revealing a phenomenon as it exists in the world as a means of gaining a deeper understanding of that individuals everyday experience (Colaizzi, 1973; van Manen, 1990). Such methodologies typically include gathering information and perceptions through inductive, qualitative methods, such as interviews, discussions, and participant observation (Vagle, 2016). Because phenomenological approaches are based in a paradigm of subjectivity and personal knowledge, and emphasize the importance of personal perspective and interpretation, they are an appropriate method for understanding subjective experiences and gaining insights into the essence of an individual's motivations and actions (Lester, 1999).

As such, phenomenology was the methodology used for this study. Interviews with parents of children with disabilities in low SES communities were conducted to determine parents' knowledge of their child's disability, participation in the special

education process, and how they interacted with the procedural rights manual.

Data Collection and Analysis

Data was collected through one-on-one interviews with parents that was transcribed for analysis. Memos were created after interviews to capture personal reflections, queries, insights and any anecdotal observations such as body language that were unable to be captured in audio format during the recording.

Data analysis occurred through multiple steps of data reduction (reducing the data to what the researcher considered important), and labeling important excerpts into categories to develop themes. Initial labeling consisted of exploring commonalities from the responses as they pertained to the four guiding questions in the study. Next I classified/coded the labeled excerpts into categories.

Delimitations and Limitations

Delimitations included the criteria for participants in the study. These included the following:

1. Participant had to be the parent or guardian and had to be the educational decision maker for a child currently receiving special education services.
2. Participants had to have a child with a current IEP or IFSP. There was no time limit set on how long a child had to have been receiving services.
3. FARM – students of interviewed parents had to qualify for free and reduced meals at their school as this was used as a socioeconomic indicator.
4. Families were recruited from inner city and urban environments. Families were initially recruited from Southern California. However, due to a limited amount of participants in Southern California, participants were also recruited

from Washington, D.C.

5. Participants must be fluent in the English language.

Due to the above delimitations, caution should be given to generalizing the results to other populations.

Reliance on volunteers as participants presented a limitation to the study. By only using volunteers it is possible that the sample was narrowed to a specific subset of parents from low SES communities. By relying on available volunteers, it is possible that a group of parents that were willing but unable to participate in the study due to competing commitments (e.g. multiple jobs, multiple children), and who may have had different experiences as they made decisions about their child's special education needs, were unrepresented. This is important to note as they may also be the parents least likely to show for meetings at the school.

Human Subjects Protections

As this study involved gathering confidential information such as names of parents, children, schools and the child's disability, all identifiable information was removed from the interview transcripts. Only this researcher will have access to the key that identifies the pseudonyms utilized in the transcripts and written results. Documents were saved as pass coded protected files. Hard copies of documents were stored in a safe that was accessible via a code or fingerprint.

Subjectivity Statement

For the past twenty years I have worked with the wealthiest of our society and the poorest of our society. I have watched how differently each group navigates the special education system for their child forcing my own skill subset to grow and change while

working in each population.

While my parents from high SES communities not only showed to every meeting, they pre-read every document, highlighted and returned an annotated version of the documents for the team's preview prior to the meeting, and came to meetings with research literature to make their case in the meeting when they disagreed with the team; yet my families from low SES communities were difficult to contact, missed meetings, said very little in meetings and asked few if any questions. Early in my career, I explained this difference in approach as parents from low SES communities simply were unmotivated to see education as a priority. Overtime this theory evolved to thinking that parents of low SES communities were juggling multiple competing priorities (i.e. multiple children, different schools, legal system, public transportation to get to multiple appointments on the same day) and some days as long as their child continued to receive services making the meeting was not a priority. Today I view parents of low SES communities differently. Yes, they have competing priorities, yes motivation can be a factor; however I also believe that their experience in the school system plays a significant factor. If they feel dismissed, unequipped to participate, overwhelmed, have a consistently changing team, poor relationships with the teachers or staff, language barriers – or any combination of these factors, a parent may be less enthusiastic about speaking in a meeting, let alone showing up for the meeting. Thus, what may appear to be an issue of motivation, is really an aftereffect of situational factors that at times are out of the control of the parent and are un- or under addressed by the school.

My background of working in special education for over eighteen years with families from low income communities factored greatly not only into my own personal

experiences in participating in special education meetings, but also in my interpretations of parental responses. Where years of working within this population gave me insight into commonalities of the norms, customs and intangible components that make their community a community, it also had the potential to not only bias me in my interpretation of their responses, but also lead me to conclude that "I've seen this before" and not explore something further because I thought I knew what someone meant rather than letting the parent speak for themselves. When interpreting parental responses in this study, I always had to determine if my analysis was speaking from my own perspective as an educator sitting at the table rather than through the parent's perspective. Because these two roles of parent of a child with a disability, and educator of a child with a disability were so closely intertwined in their desire to advocate for what was best for the child, but differed in their knowledge of the law, education and child development in relation to disability, there stood the potential for conflict in our opinions of what the best course of action might be for a child. To speak authentically for the parent I had to be cognizant of my personal predispositions, particularly in instances when I understood what a parent was saying, but had heard it so many times that I could presume what a parent meant, disagreed with how they were asking (i.e. combative, aggressive, entitled) something, or their reasons why (i.e. seeking supplemental security income). To combat any biases that arose, I kept the guiding questions of the study in mind to seek clarity in responses from parents. By remaining true to the purpose of the study, to seek to understand the parental experience, my biases were reduced.

Definition of Key Terms

IDEA	The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education (FAPE) to eligible children with disabilities throughout the nation and ensures special education and related services to those children (IDEA, 2004).
Procedural Safeguards	A guide for parents to their rights under IDEA (IDEA, 2004, Section 300.504 (c)).
LEA	Local Education Agency According to IDEA, LEA is defined as a public board of education or other public authority legally constituted within a State for either administrative control or direction of, or to perform a service function for, public elementary schools or secondary schools in a city, county, township, school district, or other political subdivision of a State, or for a combination of school districts or counties as are recognized in a State as an administrative agency for its public elementary schools or secondary schools (IDEA, 2004 ~ 34 CFR 303.23)
Poverty Threshold (also known as poverty line, poverty limit)	Minimum level of income or resources that are adequate to meet the needs of families (U.S. Census Bureau, 2017a).
Poor/Poverty	If the total income for a family or unrelated individual falls below the relevant poverty threshold, then the family (and

	every individual in it) or unrelated individual is considered in poverty. (i.e. in 2016, if a family of three reported an income of less than $19,105, the family and each of its members would be considered poor) (U.S Census Bureau, 2019)
Poverty Rate	Shows the proportion of people with income below the poverty threshold (Fontenot et al., 2018)
Income-to-Poverty Ratio	Estimates the depth of poverty and reflects how close a family's income is to its poverty threshold. It is reported as a percentage that compares a family's or an unrelated person's income with the poverty threshold (Fontenot et al., 2018) (i.e. a family with an income-to-poverty ratio of 125 percent has an income that is 25 percent above the poverty threshold)
Income Deficit	Shows how many dollars a family or an individual's income is below (or above) the their poverty threshold. For those with an income deficit, the measure is an estimate of the dollar amount needed to reach the poverty threshold (Fontenot et al., 2018)
Income Surplus	Shows how many dollars a family or an individual's income is above the their poverty threshold (Fontenot et al., 2018)
Chronic Poverty (also called long term poverty	a phenomenon where an individual or group lives in a state of poverty over an extended period typically five to seven years (Edwards, U.S. Census Bureau, 2015)

Income Poverty	When a household's income does not meet the set national minimum income considered necessary for members of that household to achieve basic standards of living. Income poverty is determined by the size of the household and the number of children in the household (U.S. Census Bureau, 2017a).
Socioeconomic Status (SES)	The social standing or class of an individual or group. It is often measured as a combination of education, income and occupation (American Psychological Association, 2019)
Generational Poverty	When a family has lived in poverty for at least two generations (McLeod & Shanahan, 1993; Mossakowski, 2008)
Situational Poverty	When a family or person's income and support has been decreased due to a specific change, such as a job loss, divorce, death or other event (Beegle, 2003).
Allostasis	the process of maintaining stability in the body during changing conditions (Shonkoff et al., 2012)
Allostatic load	the wear and tear on the body that accumulates as an individual is exposed to repeated or chronic stress (Shonkoff et al., 2012)
Disproportionality	When a minority group's numbers in special education are statistically higher than they should be (Coutinho et al., 2002; Kincaid & Sullivan, 2017)

Readability	The ease with which a reader can understand a written text. Readability can be impacted by a texts content (complexity and use of vocabulary), presentation (font size, line height, line length) (Lo, 2014)
Heuristics	Simplifying strategies (Tversky & Kahneman, 1974)
Availability Heuristic	A mental shortcut that relies on immediate examples that come to a given person's mind when evaluating a specific topic, concept, method or decision (Kahneman & Tversky, 1973)
Free and Reduced Meal (FARM)	This term is used to identify students that qualify for free and/or reduced meals at schools based on their socioeconomic status. This subsidy is intended to direct benefits to those children most in need. Children from families with incomes at or below 130 percent of the Federal poverty level are eligible for free meals. (U.S. Department of Agriculture, 2017)
Uncertainty Avoidance	One of four culture dimensions presented by Geert Hofstede that focuses on how cultures adapt to changes and cope with uncertainty. Emphasis is on the extent to which a culture feels threatened or is anxious about ambiguity. It is not risk avoidance but rather, how one deals with ambiguity. (Hofstede, 1984)

CHAPTER TWO: LITERATURE REVIEW

Based on IDEA, schools are expected to take steps to ensure that parents of a child with a disability are present at special education meetings or afforded the opportunity to participate. (IDEA, 2004). Decision making events in the special education process that must by law include a parent, include the identification of a disability, programmatic planning and implementation, and assessment of their child (IDEA, 2004). For parents to be actively involved, they need to be familiar with the intricacies of special education law as well as their parental rights to assist them in making informed decisions about their child's education. Because many of the poorest individuals in our society are often the least educated, they are often unable to access information in the same manner as their educated, affluent counterparts.

This study seeks to add to the research on parent involvement in special education by examining the decision making experiences of parents of children with disabilities and providing a perspective that will enable educators to focus on the needs of parents of low SES communities while understanding the barriers they face when advocating for the needs of their children in school.

To accomplish this goal, this literature review will explore four subjects to support the need for further research into the decision making experience of parents of low SES communities whom have a child with a disability: (1) IDEA's parental involvement requirement; (2) how poverty impacts development and learning; (3) barriers to informed decision making for parents of low SES communities; and (4) the impact of the high readability of documents.

The Systemic Literature Review

This literature search focused on the decision making process for parents of low socioeconomic communities who have a child with a disability. The search of the literature focused on topics related to parental involvement in the special education process, characteristics of parents and children in low socioeconomic communities, poverty's impact on learning, physical and neurological development, and the readability of documents provided to parents of children with disabilities. To locate literature for this review, key terms included terminology related to the areas of IDEA, poverty, parental participation in the special education process and the readability of documents. Due to the high volume of articles reviewed for the multiple topics, the following criteria were used to select the research studies to be included in the review: (a) published in a peer reviewed journal; (b) conducted in the United States; and, (c) conducted within past ten years. A mixture of qualitative, quantitative and mixed method studies were included. A comprehensive search of published studies was conducted through internet search engines and references from other articles. Five databases were used in the internet search: Education Source, ERIC (EBSCO), Google Scholar, JSTOR and Web of Science. Relevant studies were identified utilizing multiple terms. Table 1 provides a detailed list of the key terms that produced literature used in this review. The searches were limited to research conducted in the past ten years to increase relevance to current terminology and for the most recent statistical information on poverty. Current research was also used to establish where a gap in the literature remains.

Table 1

Key Terms Used in Literature Review

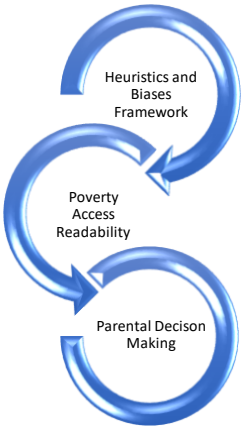
Topic	Key Terms Searched
IDEA	• Parental involvement/participation • Parental experiences in IEP meetings • Barriers to parent participation
Poverty	• Poverty amongst children in the US • Types of poverty in the US • "Poverty" + "special education" • Who are the poor in the US • Childhood poverty in the US • Characteristics of poverty • Social stratification • Intergenerational inequality
Biological Impact of Poverty	• Impact of poverty on child development • Impact of poverty on brain development in children • Socioeconomic status + health • Socioeconomic status + brain
Parental Decision Making	• Barriers to parental decision making • Parental decision making in special education • "Parent" + "special education" + "participation"
Readability	• Readability + special education

- Readability + procedural safeguards
- Parents + readability
- Parents + written communication
- Readability + socioeconomic status

This chapter will review research on poverty, access to resources for those in low SES communities, and the readability of documents to determine how each informs the decision-making process of parents of low SES communities on their child's special education services.

Theoretical Framework

Figure 1
Theoretical Framework



Heuristics & Biases Framework:

The phenomena of the parental decision-making process will be examined through the lens of the Heuristics and Biases Framework (Kahneman & Tversky, 1973). This framework derives from psychological research that addresses the question of how judgement and behavior is shaped through basic psychological processes. The framework can be used to understand how individuals both receive and process information to make decisions under circumstances of uncertainty, especially in the face of ambiguous, complicated, and/or incomplete information (Chaudry et al., 2010; Thaler & Sunstein, 2008; Tversky & Kahneman, 1974). However, it is important to note that the heuristic process itself can at times lead to systemic errors in judgement (Chaudry et al., 2010).

The heuristic process uses knowledge structures known as heuristics (simplifying strategies) that are learned and stored in memory. The heuristic process is governed by the basic principles of how knowledge is activated through availability, accessibility and applicability (Chen et al.,1999). In heuristic processing, heuristics must be stored in memory (available), be retrievable from memory (accessible), and relevant (applicable) to the task at hand (Chen et al.,1999).

Through the use of heuristics, those utilizing a heuristic process are likely to rely on information that is readily accessible such as who is delivering the information or if it is endorsed by others (Chaiken, 1980).

In light of the relative newness of this approach in understanding parental decision-making processes in the special education process, the following sections will describe examples of how the framework might improve the understanding of parental decision-making experiences while going through the special education process.

The Subjective Construal

A principle precept of social psychology is the notion of construal (Chaudry et al., 2010). The construal is defined as how individuals perceive, comprehend, and interpret the world around them, particularly the behavior or action of others towards themselves (Bruner, 1957; Griffin & Ross, 1991; Nisbett et al., 1973). Thus, rather than responding directly to environmental stimuli, an individual will construct mental representations about the environment. It is these subjective representations, or construals, that ultimately matter for a person's judgment (Chaudry et al., 2010; Ross & Nisbett, 1991).

Utilizing the lens of heuristics (Moustakas, 1994), this study aims to observe how parents in low SES communities receive and process complex amounts of information to

make decisions about their child's special education needs. Given the copious amounts of information shared with parents ranging from legal jargon, protocols and academic goals, parents must integrate multiple pieces of information to determine what they think will be in the best interest of their child with special needs. It will be helpful to know not only if parents of low SES communities are using mental shortcuts, but also if/how to what extent parents are focusing on one aspect of a complex problem and ignoring others. It will also be useful to know if there is similarity in the type of information they are ignoring. This study will aim to identify answers to these questions.

Cognitive Biases

A critique of the construal process is that it often leads to a simplified representation of the world through the use of heuristics, a type of cognitive "shortcut" strategy to simplify decisions (Chaudry et al., 2010; Tversky & Kahneman, 1974). Heuristics, or simplifying strategies, are helpful for making sense of a complex environment and allowing an individual to arrive at a conclusion that is both reasonable and satisfying for their understanding of the information (Simon, 1955). Heuristics help the individual scrutinize complex amounts of information when their efforts are compromised by limitations to their cognitive capacity and or motivation (Chaudry et al., 2010).

Multiple studies have shown that the quality of an individual's decisions declines when there are too many choices to select from, because too many options lead to information overload and increased decisional conflict (Botti & Iyengar, 2006; Shafir et al., 1993; Tversky & Shafir, 1992). The heuristic process is useful when one is faced with the challenge of making decisions about issues with which one is unfamiliar, that are

complex, or when the individual has little practice in making such decisions (Chaudry et al., 2010). Additionally, when the most appropriate decision comes from considering a complex array of factors that may be unclear or may have competing values, an individual's cognitive capacity may be stretched too far, thus compromising their decision-making (Chaudry et al., 2010). For some, the heuristic process, utilizing simplifying strategies (heuristics) to make information available, accessible and applicable, may result in reasonable decisions, (Simon, 1955: Gigerenzer & Brighton, 2009), while in other cases it may lead to suboptimal or undesirable outcomes (Tversky & Kahneman, 1974). This may be in part due to a type of heuristic known as an *availability heuristic* where people's perceptions and judgments are influenced by how readily and easily examples of a given topic come to mind (Kahneman & Tversky, 1973; Schwarz et al., 1991). Consistent with availability heuristic, individuals using this strategy are more likely to utilize information in their decision-making process when that information is more familiar, recent, or significant (Chaudry et al., 2010).

Another type of simplified heuristic strategy used in the construal process is "category-based judgements" (Bruner, 1957). In this construal process, individuals simplify their understanding of the environment by relying on knowledge of a particular category or class of information to arrive at a conclusion about a particular case (Kahneman & Tversky, 1973). For example, identifying an object as a chair gives an individual a host of information about the object such as its intended use, shape, material and so forth (Chaudry et al., 2010). Applying this process to special education, a parent may judge the quality of a program on subjective information, such as the neighborhood in which the program is located. The parent may judge the program as less successful

because it is in a less desirable neighborhood. The location of the program may provide some information about the quality of the program, but is limited in its value for determining the overall quality of the program. The location of a program cannot reveal information about the attributes of the teachers, the students, or the level of learning occurring in the classroom. Nor can it determine the level of knowledge the teachers have about student learning or how attentive the teachers are to adapting lessons to student's needs. In such examples, category-based inferencing may have particular relevance in understanding parental decision-making in the special education process in determining how parents conclude what academic programming is best for their child.

Another way of looking at the example where a parent may be disinterested in a program if they perceive it to be in a poor neighborhood, is if they believe programs in wealthier areas of town are better. By identifying programs by categorical area, a parent may deem the program unworthy because it will have limited resources, and possibly surround their child around children they do not want their child around. However, the opposite may hold true if the parent believes that the program is located in a "nice" neighborhood. The assumption may then be that the academics are better and that there are more resources available. Thus, rather than seeking out information and evaluating the programs on the strengths and weaknesses of their academics, parents may rely on category based judgements about the value of a particular setting or program.

The heuristic framework of utilizing simplifying strategies (heuristics) to make information available, accessible and applicable, in the context of how parents perceive, comprehend, and interpret the world around them (construal), supports this study given the complexity of knowledge needed when making decisions about a child's special

education needs. Such complexity includes the level of readability of procedural manuals and limited access to resources. This study seeks to understand how parents in low SES communities interpret the world around them and how it impacts their decision making on the needs of their children with special needs.

Policy Context

Based on the requirement of parental participation throughout the special education process under IDEA (2004) and the low readability of printed materials such as the Procedures Safeguards Manual to inform parents of their legal rights, this study will explore how parents of low SES communities gather information to make educational decisions about their child's special education needs. This study will also build upon the 2010 work of Audrey Trainor who identified the capital resources parents perceived as necessary to participate in the special education process.

For this study, readability will be defined as all of the interactions that affect the successful use of material, including the ability to understand the conveyed information, read the information at an optimal speed, and find the information of interest (Dale & Chall, 1948; Pizur-Barnekow et al., 2010).

The Individuals with Disabilities Education Act Parental Involvement Requirement

Parent involvement and participation are a recurring focus of education policy and practice. It has been a core concept since the inception of the Individuals with Disabilities Education Act (IDEA) in 1997 (FEDC Brief, 2012; Trainor, 2010). Key components of the original law and its reauthorization in 2004 include parent participation in Individualized Education Program (IEP) planning; home-school collaboration, and decision-making opportunities for parents in all aspects of their child's education,

including the evaluation, placement, and implementation of services. Parent participation ranges from passive to assertive and can vary in its intensity, focus, and area (FEDC, 2012; Trainor, 2010). Although parents of children with disabilities have advocated at both a local and a systems level to provide their children with appropriate and inclusive educational opportunities, some parents exercise their involvement solely as representatives for their own child at required meetings (FEDC, 2012). Because schools are expected to include parents in the decision-making process about their child's education, schools must learn how to best include and educate parents of low SES communities when the primary mode of communication from the school is through print culture.

Collaboration between parents and schools is critical to accurate educational planning for students with disabilities and is the tenet of two principles of IDEA: parent participation and procedural due process (IDEA, 2004). Despite the inclusion of these laws, parents often arrive at special education meetings with feelings of anger, anxiety, alienation, apprehension, embarrassment, frustration, guilt, and intimidation (Bateman & Linden, 1998; Besnoy, 2006; Cantor & Cantor, 1995; Flynn, 2006; Haley et al, 2013; Hammond et al., 2008; Matthews, et al., 2011; Smith, 2001). Parents have also reported feeling overwhelmed, not only by the number of staff present at meetings but also the amount of professional jargon used at meetings (Haley et al, 2013). Laws such as IDEA, the No Child Left Behind Act (NCLB) and Every Student Succeeds Act (ESSA) formalize the roles and expectations of parental involvement in the special education process (IDEA, 2004; No Child Left Behind [NCLB], 2002; Every Student Succeeds Act [ESSA], 2015. IDEA requires schools to safeguard parental involvement so that it is both

meaningful and confirms a parent's understanding of their procedural rights and the proceedings. IDEA requires that parents be included in all aspects of their child's educational programming for students receiving special education services (Table 2). Although the requirements of IDEA can be compartmentalized into broad categories, a few have been selected to review for this study as they pertain to the parent decision making process. Table 2 identifies the parent participation requirements as outlined by IDEA, corresponding section numbers, and a paraphrased description of each requirement. It is noteworthy to mention that the updates made to IDEA through ESSA did not change these parts of IDEA.

Table 2

Parent Participation Requirements Under the Individuals with Disabilities Education Act

Requirement	**34 CFR Citation**	**General description (Paraphrased from the federal regulations)**
Communication Presented to Parents		
Prior Notice	§ 300.503	The local educational agency (LEA) must provide written notice, in a language that may be understood by the parent, proposing or refusing to initiate or change the identification, evaluation, or educational placement of the child or the provision of a Free Appropriate Public Education (FAPE) to the child.
Procedural Safeguards Manual	§ 300.504	The LEA must give parents a copy of the Parents' Rights and Procedural Safeguard (an explanation of all procedural safeguards under IDEA) at least once each school year as well as upon an initial referral; whenever a parent request an evaluation; at the receipt of the first due process

		complaint (filed by the parent) in a school year; and at the request of a parent.
Decision Making and Planning		
Consent (testing, provision of services)	§ 300.300	The parent must be fully informed about, understands and agrees, in writing, to a specific activity related to the provision of special education services, such as testing or the implementation of the IEP for their child. Consent is voluntary and may be revoked at any time.
Parent	§ 300.300 (a-c) § 300.300 (d)(3)	The LEA must obtain informed, written consent prior to an initial evaluation, the initial provision of special education and related services, or the reevaluation for special education services. The LEA may not use a parent's refusal of consent to one activity or service to deny or refuse any other service, benefit, or activity.
Eligibility Determination	§ 300.306	Based on the results from evaluations and assessments, both the qualified professionals and the parent of the child are to determine if the child is eligible for services.
Parent as an IEP team member	§ 300.321	The IEP team for each child eligible for special education services must include a parent of the child.
Parent participation in IEP team meetings	§ 300.322 §300.501(a)	The LEA must ensure that a parent of the child with a disability is at each IEP team meeting or is provided the opportunity to participate. The LEA must notify parents of IEP meetings early enough to ensure that they will have the opportunity to attend the

		meeting. The LEA must schedule IEP meetings at a mutually agreed upon time and place.
Educational placements	§ 300.327 §300.501(c)	The LEA must ensure that a parent is a member of any group that will make decisions about the educational placement of their child.
Alternative means of meeting participation	§ 300.328 § 300.501 (c)(3)	The parent and the LEA may agree to use an alternative means of meeting participation, such as conference and video calls.
Information Access		
Opportunity to examine records	§ 300.501 (a)	The parent must be allowed an opportunity to inspect and review all of their child's education records regarding the identification, evaluation, and educational placement of their child; and the provision of a Free Appropriate Public Education (FAPE) to their child.
Systems-Level Decision Making and Planning		
State Advisory Panel	§ 300.168	The State Advisory Panel that provides policy guidance regarding special education and its related services must include parents of children with disabilities.

Despite these legal mandates, the law as it is written assumes equal skills among parents. For those with limited education or low reading skills, guaranteeing a prior written notice or the provision of a procedures manual means little if the parent is unable to access the information in those documents. Section 300.300 of IDEA states that parents must be fully informed about, understand and agree, in writing, to a specific activity related to the provision of special education services for their child; yet how does a parent do this if they are unable to access the information in the written material such as

the safeguards manual? Although the law is meant to protect the rights of those with disabilities, those who must implement the law are challenged in the contexts of highly diverse educational and linguistic backgrounds within their parent populations.

Review and Critique of the Scholarly Literature

Today, as in the past, education is perceived as the gold standard exit ramp from a life of poverty (Holleb, 1972; Gans, 1995; Levine & Nidiffer, 1996; Mortenson, 1998; Beegle, 2003). This study seeks to understand the decision making experiences of parents in low SES communities. Poverty effects children's development and has long-term impacts that can result in long-term deprivations into adulthood. It is therefore important to understand what poverty is and how it impacts learning in the classroom, in order to understand the magnitude of the decisions that parents have to make for their children. The next sections will describe how poverty is defined, who are considered poor in the U.S., generational poverty, and the link between poverty and disability.

Poverty

From 2000 through 2002, research found that 28% of children in the U.S. with disabilities lived below the federal poverty line as compared to 16% of children without disabilities (Fujiura & Yamaki, 2000; Park et al., 2002). By 2012, the number of children with special needs living below the federal poverty line reduced to 24% (Kids Data Lucile Packard Foundation, 2012), yet continued to be significant. As of 2017, in the United States there are nine states that have a fifteen point poverty gap between those ages five through seventeen with and without a disability and twenty six states with at least a ten point gap indicating that in those states, the poverty rate is ten to fifteen or more percentage points higher for those children with a disability than without a

disability (Kraus et al., 2018).

However, the effects of poverty are not limited to financial impacts. Biologically, children living in low SES communities have been shown to demonstrate an altered neuroendocrine stress response as well as compromised executive function skills in the area of self-regulation (Raver et al., 2013). Poverty and poverty-related stressors have also been associated with higher allostatic load (the wear and tear on the body that accumulates as an individual is exposed to repeated or chronic stress), lower executive function abilities, and compromised self-regulation skills in young children (Hackman & Farah, 2009; Hanson et al., 2013; Raver et al., 2013).

In the United States, many who ascend from poverty into the middle class do so primarily by obtaining a college education (Higginbotham & Weber, 1992; Beegle, 2003). In the U.S, however, individuals living in poverty are the least likely to become literate and achieve a college education (Mortenson, 1998; Beegle, 2003). Individuals living in chronic or intergenerational poverty tend to remain poor, and historically have achieved a low level of formal education, generation after generation (Beegle, 2003). Research on the-intersections between poverty, children, and disabilities reveals that children with disabilities are significantly more likely to live in poor families (Parish et al., 2008). In 2009, Wagmiller and Adelman identified key characteristics of poverty in the United States. They found that 35% of the children born between 1970 and 1990 experienced living in poverty prior to turning sixteen years of age. Individuals who were identified as poor in childhood had a greater likelihood of being poor in adulthood. Additionally they found that African Americans who experienced childhood poverty had significantly more difficulty escaping poverty than their white counterparts. In 2011,

Wright, Chau and Aratani built upon this research to demonstrate who America's poor are based on ethnicity, family composition and geography. They found that poor children are more likely to be African American, Hispanic or Native American and that official poverty rates were highest for children ages six and younger. Additionally, having parents that are immigrants adds an additional risk factor to living in poverty.

Defining Poverty

In his book, What's Class Got to Do With It?, Michael Zweig defines poverty as a state of deprivation, where individuals lack typical or socially acceptable amounts of money or material possessions (Zweig, 2004). In the United States, the most common measure of poverty is the *poverty threshold* established by the U.S. government (U.S. Census Bureau, 2017a). This measure recognizes poverty as a lack of goods and services commonly taken for granted by members of mainstream society (Schwarz, 2007), and is defined by the U.S. Census Bureau as the minimum level of income or resources that are adequate to meet basic needs (Ravallion et al., 1991; U.S. Census Bureau, 2017a). Although this measure is the most widely used, it is considered to significantly underestimate the needs of families (Semega, Fontenot & Kollar, 2017; Jiang, Granja & Koball, 2017). In 2016, the poverty threshold, also known as the poverty line or poverty limit, for a family of two adults and two children was $25,465 (U.S Census Bureau, 2018), an annual income that is insufficient for a family of four to achieve a basic standard of living in many areas of the U.S.

A review of poverty research elicits multiple terms to describe poverty, including poor, near poor, chronic poor, low income, extreme poverty, deep poverty, absolute poverty, collective, case, cyclical and destitute poverty. These terms are often used

interchangeably, while at other times they describe different aspects of poverty. The terms used to describe poverty are as varied as the causes of poverty. For this study, terminology used and definitions set by the U.S. Census Bureau will be used to define poverty. Poverty, according to the U.S. Census Bureau is determined by money income thresholds for a family or unrelated individuals in a household. If the total income for a family or unrelated individuals falls below the poverty threshold, the family, and every individual in it, or unrelated individual is considered to be living in poverty (U.S. Census Bureau, 2019).

It is important to note, that various studies and organizations that focus on poverty use definitions from the U.S. Census Bureau with terminology such as low income, deep poverty and extreme poverty. The U.S. Census Bureau's Poverty Specialty Area only defines poverty in terms of percentages (per personal communication, February 4, 2019). The Bureau categorizes people as "not in poverty, in poverty or below poverty" to describe their economic situation (Fontenot et al., 2018). Terminology such as the income-to-poverty ratio, the income deficit, and income surplus describe additional aspects of economic well-being. Where the poverty rate demonstrates the proportion of people with income below the poverty threshold, the income-to-poverty ratio ascertains the depth of poverty and reflects how close a family's income is to the poverty threshold (Fontenot et al., 2018). The income-to-poverty ratio is reported as a percentage that compares a family's or an unrelated person's income with the poverty threshold (Fontenot et al., 2018). For example, a family with an income-to-poverty ratio of 125 percent has an income that is 25 percent above the poverty threshold. Conversely, a family that has an income-to-poverty ratio of 1.25 has an income that is below 125

percent of the poverty threshold. The income deficit or income surplus demonstrates how many dollars a family or an individual's income is below, or above, the poverty threshold (Fontenot et al., 2018).

This literature review will focus on income deficits. For those that have an income deficit, the measure is an estimate of the dollar amount needed to reach the poverty threshold (Fontenot et al., 2018). The Bureau classifies income-to-poverty ratios for those with income below the poverty threshold as follows - those below 50 percent of poverty ("Under 0.50"), those below 125 percent of poverty ("Under 1.25"), those below 150 percent of poverty ("Under 1.50") and those below 200 percent of poverty ("Under 2.00") (Fontenot et al., 2018).

The U.S. Census Bureau considers an individual impoverished if the resources they share with others in the household are not enough to meet their basic needs (U.S. Census Bureau, 2017a). The Bureau's official measure of poverty determines poverty by comparing pre-tax income against the cost of a minimum food diet in 1963 times three (U.S Census Bureau, 2017a). The Bureau assumes that all individuals that reside together who are related by birth, marriage or adoption, share income (U.S. Census Bureau, 2017a).

According to the Bureau, income poverty occurs when a household's income does not meet the set national minimum income considered necessary for members of that household to achieve basic standards of living (U.S. Census Bureau, 2017a). In the U.S., income poverty is determined by the size of the household and the number of children in the household. The depth of poverty is measured through an income-to-poverty ratio that measures how close a family or individual's income is to the poverty threshold. Table 3

shows the values of the poverty threshold according to the U.S Census Bureau (U.S. Census Bureau, 2018b).

In the United States, a person qualifies as living in poverty if they have an income below the poverty threshold. While poverty thresholds vary by family size and household composition, for a single individual under the age of 65 in 2018, living in poverty would be an income below $13,064.

Table 3

Poverty Thresholds for 2018 by Size of Family and Number of Related Children

	Related children under 18 years								
Size of family unit	**None**	**One**	**Two**	**Three**	**Four**	**Five**	**Six**	**Seven**	**Eight or more**
One person (unrelated individual):									
Under age 65	13,064								
Aged 65 and older	12,043								
Two people									
Householder under age 65	16,815	17,308							
Householder aged 65 and older	15,178	17,242							
Three people	19,642	20,212	20,231						
Four people	25,900	26,324	25,465	25,554					
Five people	31,234	31,689	30,718	29,967	29,509				
Six people	35,925	36,068	35,324	34,612	33,553	32,925			
Seven people	41,336	41,594	40,705	40,085	38,929	37,581	36,102		
Eight people	46,231	46,640	45,800	45,064	44,021	42,696	41,317	40,967	
Nine people or more	55,613	55,883	55,140	54,516	53,491	52,082	50,807	50,491	48,546
Source: U.S. Census Bureau (2018)									

Who Are The Poor?

In 2017, the official poverty rate was 12.3 percent (39.7 million) (U.S. Census Bureau, 2018). Of the 18.5 million people in 2017 who had family incomes below one-

half of the poverty threshold, 31.6 percent (5.9 million) were under the age of 18 (Fontenot et al., 2018). Among all children under 18 years of age in the United States, 43 percent lived in low income families and 21 percent, approximately one in five children, lived in poverty (Jiang et al., 2017). This means that children are overrepresented among the nation's poor. Children as a whole represent 23 percent of the population but make up 33 percent of all people living in poverty (Jiang et al., 2017). Over the past two decades, families living in poverty have experienced a steep decline in the amount of aid they receive from public programs, while families with incomes between 50 and 150 percent of the poverty line have received an increase in assistance from public programs (Shalom et al., 2012; Shaefer & Edin 2013).

The most recent U.S statistics show that for children under the age of 18, 19% live in poverty (Kids Count Data Center, 2017) and 9% live with incomes below 50% of the poverty threshold (Kids Count Data Center, 2017a). Of those children, 21% of children ages 0-5 live in poverty and 19% ages 6 to 17 live in poverty (Kids Data Center, 2017c).

Race And Poverty

Racial and ethnic minorities have historically intersected with low SES in the United States. The percentage of children living in poverty under the age of 18 varies widely by race and ethnicity (Table 4) (Kids Count Data Center, 2017a). Black, American Indian and Hispanic children are disproportionately represented among those that are living in poverty (Jiang et al., 2017). In the United States, Blacks and Hispanics are more likely than Whites to experience long-term socioeconomic disadvantages that begin early in life (Mossakowski, 2008). Recent U.S. estimates indicate that 34% of African Americans live in poverty, 28% of Hispanics and 12% of Whites (Kids Count

Data Center, 2017b). African Americans and Hispanics are four to five times more likely than Whites to be chronically poor for two years (Mossakowski, 2008).

Generational Poverty

Generational poverty occurs when a family has lived in poverty for at least two generations. Chronic poverty prior to age five is a significant predictor of symptoms of depression and anxiety in childhood, independent of current poverty status (McLeod & Shanahan, 1993; Mossakowski, 2008). SES is fundamental to understanding educational disparity, because it structures an individual's unequal access to resources for knowledge acquisition, money, material assets, lifestyle and social networks. Examples of

Table 4

Child Poverty Rates by Race/Ethnicity in the United States in 2016

Race/Ethnicity	Number	Percent
African American	3,468,000	34%
American Indian	242,000	34%
Hispanic or Latino	5,124,000	28%
Two or More Races	944,000	20%
Asian & Pacific Islander	441,000	12%
Non-Hispanic White	4,326,000	12%
Total	14,116,000	19%

environmental and neurobiological ramifications associated with poverty include prenatal exposure to alcohol or lead (Grunau, Whitfield, & Davis, 2002), very low birthweight (Goodlad et al., 2013; O'Connor & Paley, 2009) and experiencing multiple

risk factors in early childhood (Shaw et al., 2001). Very low birth weights have been linked to impaired brain growth that leads to lower cognitive and executive functioning (Morgan et al., 2017). Maternal smoking and substance abuse during pregnancy have been linked to lower inhibitory control (Galera et al., 2011), and generalized cognitive deficits (Kodituwakku, 2009). Socioeconomic disadvantage may also increase the risk for both behavioral and cognitive disorders (Claycomb et al., 2004). A high correlation has been associated with many of these neurobiological/environmental risk factors and racial/ethnic minority status (Donovan & Cross, 2002; Macmillian & Reschly, 1998; Morgan et al., 2017; U.S. Census Bureau, 2012).

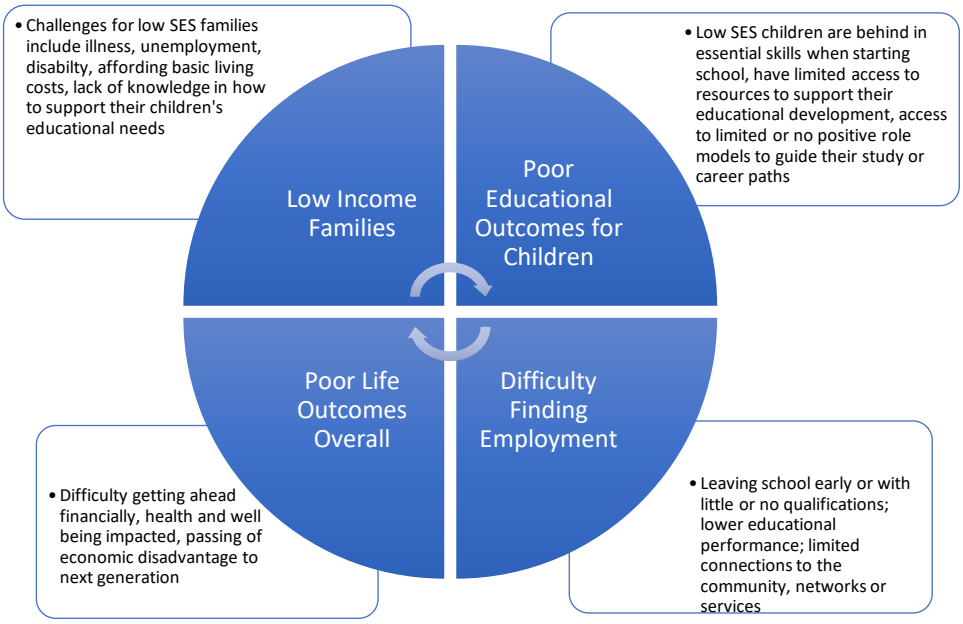
Research on generational poverty defines long term/chronic poverty in two terms, "transient poverty" (1 to 7 years) and "persistent poverty" (8 to 16 years) (McDounough & Berglund, 2003). Those living in chronic poverty are distinguished from those that are poor by their extended duration of living in poverty (Hulme & Shepherd, 2003). Individuals who are poor for four years have a 90% probability of being poor their entire life (Yaqub, 2002). Those who are poor for five years or more have a higher probability of remaining poor for the duration of their lives (Corcoran, 1995; Yaqub, 2002; Hulme & Shepherd, 2003). Those living in chronic poverty increase the likelihood of the intergenerational transmission of poverty to subsequent generations (Harper et al., 2003; Hulme & Shephard, 2003). Research by Harper, Marcus and Moore (2003), provides a framework (Figure 2) for the intergenerational transmission of poverty and the ways in which certain events and types of childhood raise the likelihood of children maturing into poverty and becoming members of poor households.

Poverty and Disability

In 2017, of the 2,885,169 children ages five through seventeen who were identified with a disability, 810,084 lived below the poverty line (U.S. Census Bureau, 2017d). Understanding the link between poverty and disability is paramount, as those that live in poverty are more likely to have a disability (Fujiura & Yamaki, 2000; Groce, Kett, Lang, & Trani, 2011). For families with children that have a disability, the poverty rate is higher (Fujiura & Yamaki, 2000; Swafford et al, 2015). When compared to families of children without a disability, families of children with disabilities face additional financial burdens such as the cost for therapy and adapting home environments (Parish et al, 2008).

Figure 2

Childhood Experiences that Support Transmission of Poverty from Childhood to Adulthood



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There is a bidirectional relationship between poverty and disability whereby poverty, through exposure to environmental hazards, leads to disability, and disability, by way of its increased financial burdens leads to poverty (Kiregu et al., 2016; Parish et al., 2008; Pinilla-Roncancio, 2015). This overlapping cycle perpetuates a cycle of poverty, infirmity and disengagement for families of low SES communities (Parish et al., 2008). The chronically poor are at a greater risk of poor health and injuries that may lead to disability via a number of routes. The chronically poor often live in unsanitary and substandard housing, are unable to afford nutritious food, are more likely to have unsafe/dangerous jobs, and live in areas where there is a high probability that they will experience or witness violence (Groce et al., 2011). Research on the impact of poverty on the neurological and physiological development of children reflects links to academic achievement gaps and long term mental and physical health deficits (Blair & Raver, 2016; Evans, 2004; Shonkoff et al., 2012).

To fully understand the totality of what parents are asked to do when asked to make an informed decision about the education of their child with a disability, it is important to understand the intersection between environment and educational attainment of the parent and how these dueling forces shape their decision-making capacity. Given the neurological and biological effects of poverty, it is possible that parents too are suffering from debilitations similar to those of their child with special needs. The next sections will explore the biological and cognitive impact of poverty and how a chronically elevated physiological stress response is a plausible model for how poverty affects the brain and eventually interferes with academic achievement for students and decision-making capacities for their parents.

The Biological Impact Of Poverty

Given the large percentage of children living in poverty, it is important to consider research on the biological impact of living in poverty. Such research goes to the heart of understanding the depth of decision-making needed for parents of low SES communities that have a child with a disability. Understanding how poverty impacts development sheds light on the impact it has, not only on the child's development but also on the development of the parent if they have grown up in impoverished environments themselves or have been living in poverty for an extended duration. These biological and related psychological responses to stressors have been hypothesized as underlying explanations for health and cognitive disparities among children as it relates to SES (Hackman & Farah, 2009; Noble et al., 2012). The experiential differences between SES classes also have negative effects on the brains of individuals from low SES communities (Brito & Noble, 2014).

Cognitive Implications of Poverty

Research on poverty's impact on both the neurological and physiological development of children links both academic achievement gaps as well as the lifelong effects of poverty to physical and mental health deficits (Blair & Raver, 2016; Evans, 2004; Shonkoff et al., 2012). It is estimated that by the age of five, chronic poverty, a phenomenon where an individual or group lives in a state of poverty over an extended period of time, typically five to seven years, is associated with a reduction of IQ by six to thirteen points (Brito & Noble, 2014; Brooks-Gunn & Duncan, 1997; Hulme & Shepherd, 2003). Socioeconomic status accounts for approximately twenty percent of the variance in childhood IQ (Gottfried et al., 2003). These disparities in cognitive development can outweigh disparities in physical health, possibly explaining and contributing to the continuance of poverty across generations (Brito & Noble, 2014). Research on the biological impact of poverty suggests that socioeconomically disadvantaged children tend to experience less linguistic, social, and cognitive stimulation from their caregivers and home environments than children from higher SES homes, which may account for a portion of the observed variance in IQ scores (Kuhl, 2007; Rowe & Goldin-Meadow, 2009).

Toxic Stress and Poverty

Students living in lower SES environments experience stress at amplified levels. The terminology of what to call this stress varies by field to include toxic/chronic stress (Shonkoff et al., 2012; Evans & Kim, 2013; Evans & Schamberg, 2009), post-traumatic stress disorder (Cook et al., 2017; Kiser, 2007), complex post-traumatic stress disorder (Cook et al., 2017; Golin et al., 2017) and chronic trauma (Pressley & Smith, 2017; Van

der Kolk, 2017). What is consistent is the effects of toxic stress on the brain and body's development. The consequences of poverty have been linked with several risk factors such as poor nutrition, unsupportive parenting, limited caregiver education and high levels of traumatic and stressful life events (Luby et al., 2013).

Unfortunately, children in living poverty are often exposed to traumatic events of death, violence, domestic violence, drugs and neglect on a daily and ongoing basis. In some cases, these traumatic events can occur repeatedly over time for months or years at a time. It is estimated that more than 80% of children living in inner-city neighborhoods have been exposed to violence both in their neighborhoods and schools (Hart et al., 2013). It is estimated that about one-fifth of children nationwide have been exposed to more than one type of victimization and many are exposed to multiple types of victimization involving multiple perpetrators (Turner et al., 2010). Children with past or ongoing developmental trauma may present with dissociative disorders that are similar to their adult forms and symptomology (Sar, 2011).

Physical Response to Stress.

Physically, when the stress response is elicited for a prolonged period, it causes excessive demands on the body to maintain allostasis, the process of maintaining stability in the body during changing conditions (Shonkoff et al., 2012). This constant reprogramming of neural circuits influences a physiological response to stress that causes chronic dysregulation across multiple regulatory systems (Shonkoff et al., 2012).

Other studies have shown that a repeated high level activation of the body's stress system, especially in early childhood, can alter chemical processes in cells and

lead to changes in the chemistry of an individual's DNA (McEwen & Gianaros, 2010). These chemical changes can disable genes and prevent the brain from properly regulating its response to stress. Researchers have drawn a link between this neurochemical dysregulation and the development of chronic health problems such as depression, obesity, diabetes, hypertension, and coronary artery disease (Vaillancourt & McDougall, 2013).

Academic Impact of Poverty and Stress

Academically, the effects of chronic stress can impact the development and maturation of brain centers involved in learning (Shonkoff et al., 2012). For younger children, continuous exposure to heighted levels of stress can lead to less outwardly visible but permanent changes in their brain functions and structure (Shonkoff et al., 2012). Because the bodies of younger children are still developing, they are more sensitive to hormonal and chemical fluctuations in the body (Shonkoff et al., 2012), and these developmental alterations can lead to functional differences in learning, memory and other aspects of a child's executive functioning (Obradović, Portilla, & Boyce, 2012). Research by Evans and Schamberg (2009) suggests that the longer a child lives in poverty, the greater the amount of stress the child experiences. The greater the amount of stress experienced in childhood, the worse the child's working memory as a young adult (Evans & Schamberg, 2009).

The Brain And Poverty

Advances in neuroimaging methods have made it possible to examine the complex interactions between genetic and environmental factors that influence structural brain development. In recent years, research investigating the association between SES

status and brain development have found significant links between SES and changes in brain structure, particularly in areas related to memory, executive control, and emotion (Brito & Noble, 2014).

Experiential differences among children from different socioeconomic backgrounds have been correlated to disparities in both the quantity and quality of linguistic interactions, which has been associated with developmental differences in the cortical regions in the left hemisphere that support language (Kuhl, 2007). Additionally, the experiences of chronic stress have negative effects on the hippocampus (supports memory and mood) (McEwen & Gianaros, 2010; Tottenham & Sheridan, 2009), the amygdala (important for detecting and responding to threats in the environment) (McEwen & Gianaros, 2010; Tottenham & Sheridan, 2009), and areas of the prefrontal cortex (important for decision making and regulating emotions, impulsivity, and autonomic and neuroendrocrine function) (McEwen & Gianaros, 2010); structures which are linked together both anatomically and functionally (McEwen & Gianaros, 2010). Neurologically, the hippocampus and prefrontal cortex are each disrupted and heavily impacted by chronic physiological stress (Lupien et al., 2007). Multiple studies support the idea that working memory resides in the prefrontal cortex, but is influenced by hippocampal and possibly amygdala interactions with the prefrontal cortex (LeDoux, 2003; Lupien et al., 2007).

Overexposure to a combination of multiple, activated body response systems such as the neuronal, endocrine, and cardiovascular systems, alters the body's ability to respond efficiently to environmental demands (Evans & Schamburg, 2009). Longer, more frequent exposure to environmental stressors accelerates wear and tear on the body.

Chronic environmental stressors cause the body to utilize multiple physiological systems to meet those demands, but at higher levels of activity (Evans & Schamburg, 2009). However, when environmental demands are low, individuals who have maintained a higher allostatic load (the wear and tear on the body that accumulates as an individual is exposed to repeated or chronic stress) burden will be less efficient in turning off the multiple physiological resources utilized to deal with chronic demands (Evans & Schamburg, 2009). Chronically elevated physiological stress responses is thus a plausible model for how poverty could get into the brain and eventually interfere with academic achievement (Lupien, et al., 2006).

It is important to note however, that when examining SES disparities in structural brain development, additional factors should be considered. Factors such as the age of the child should be considered given the brain's structural changes across childhood and adolescence (Brito & Noble, 2014; Lenroot & Gieed, 2006). However, it is notable that developmental deficits associated with poverty have been detected as early as infancy (Luby et al., 2013).

For this study, knowing the neurological, biological and physiological effects of poverty, shed light on not only the scale of the decision parents have to make for their child with special needs but the importance of understanding the information needed for the decision they are making. Key takeaways from the research on poverty illuminate the following: 1) SES is fundamental to understanding educational disparity because it structures an individual's unequal access to resources for knowledge acquisition; 2) chronic poverty is associated with a reduction of IQ by six to thirteen points (Brito & Noble, 2014; Brooks-Gunn & Duncan, 1997; Hulme & Shepherd, 2003); 3)

economically disadvantaged children tend to experience less linguistic, social, and cognitive stimulation from their home environments (Kuhl, 2007), and 4) those who live in poverty are statistically more likely to have a disability.

It is reasonable to conclude then that the effects of poverty experienced by the children of low SES are the same effects felt by the parents living in low SES. This supports the notion that just as lessons should be modified for students with a disability, given the debilitating effects of poverty, parents of low SES communities may also benefit from additional supports when making decisions about their child's special education needs.

Disproportionality and Special Education

The disproportionate representation of minority children in special education is a long-standing concern. An appropriate response to end disproportionality representation, inclusive of factors contributing to disproportionality, provide a foundation for this study. Given the high poverty rates among minorities, the biological and educational impacts of poverty and the complex intricacies of decision making for parents of low SES communities; parents of students that are more likely to be identified for special education services may be least prepared to make decisions that will decrease minority overrepresentation in special education. By identifying how parents of low SES communities experience the decision making process for their children will provide necessary information that can be examined and lead to appropriate responses.

Disproportionality in special education refers to the extent that group membership affects special education identification and its outcomes (Coutinho et al., 2002; Kincaid & Sullivan, 2017). When a minority group's numbers in special education are

statistically higher than they should be compared to their representation in the U.S. population, they are considered to be disproportionate (Coutinho et al., 2002; Kincaid & Sullivan, 2017). The overrepresentation of minorities in special education has been one of the more persistent and complex issues reviewed in special education research over the past fifty years (Chin & Hughes, 1987; Dunn, 1968; Finn, 1982; Hosp & Reschly, 2004; Oswald et al., 1999; Parrish, 2002; Skiba et al., 2006). However, new research by Morgan and colleagues (2015) posits that minorities are underrepresented in special education when compared with otherwise similar White children.

The reauthorization of IDEA in 2004, requires that Local Education Agencies (LEAs) monitor their rates of disproportionate identification in special education. Section 618(d) of IDEA requires States to collect and examine data to determine if significant disproportionality based on race and ethnicity is occurring in the State and the LEAs of the State in three areas: identification of specific disabilities, placement in educational settings of students receiving special education services and the incidence, duration and type of disciplinary actions including suspensions and expulsions of students receiving special education services (IDEA, 2004). IDEA, however, does not define "significant disproportionality." The regulations do not explicitly define the term either. Instead, the regulations require States to use a standard methodology for the analysis of disproportionality, which includes States setting a threshold above which disproportionality in the identification, placement, or discipline of children with disabilities within an LEA is significant (OSEP, 2017).

Although there have been decades of research on racial disparities in special education, disproportionality was not mentioned in the law until 1997. In 1997, IDEA

was amended to require local education agencies (LEA) to report the amount of disproportionality occurring in their special education programs both generally and for specific disabilities (Morgan et al., 2017). In 2004, IDEA was reauthorized again and provided further guidance to LEAs on monitoring and reporting on disproportionality (Kramarczuk & Tefera, 2017). If LEAs are found to have disproportionality in their systems, they are required to review their eligibility policies and procedures and their funding reallocated (Morgan et al., 2017). If LEAs revise their procedures, they must publicly report on the revisions made to their eligibility policies and procedures (Morgan et al., 2017.)

Relationship of SES to Disproportionality

The research on disproportionality includes the over- and under-representation in the high incidence disabilities categories of learning disabilities, intellectual disabilities, and emotional disabilities as well as in gifted and talented programs (Artiles & Bal, 2008). Patterns at the intersections of race, socioeconomic status and disproportionality in special education are areas of contradiction and contention in the research especially in the areas of sampling dimensions such as unit of analysis (student, school, district), geographic context (district, state, region, nation), and the specific covariates examined (Kincaid & Sullivan, 2017). Contradictory findings have sparked an intense debate given the conflicting and potentially problematic implications for future policy and practice (Kincaid & Sullivan, 2017; Cohen et al., 2015; Morgan et al., 2015; Skiba et al., 2016). In this debate, the relationship between SES and race are often singled out as some researchers attribute the racial disparities associated to disproportionality to the potential environmental and neurobiological ramifications of poverty (Kincaid & Sullivan, 2017).

Skiba et al. (2005) notes that to explain racial and ethnic overrepresentation in special education entirely to disadvantages associated with poverty is simplistic at best, because although educational failure is a part of the eligibility criteria for special education services, it is not the only criteria for any disability category. In parsing out whether the inclusion of poverty as a variable in a multivariate analyses can explain ethnic and racial overrepresentation in special education, Morgan et al.'s (2015) finding that the inclusion of sociodemographic variables reduces the influence of ethnicity and race to non-significance is consistent with other studies (Hibel et al., 2010; Morgan et al., 2015; Shifrer et al., 2011) that conclude that SES accounts for the variance attributed to race. However, another body of research (Coutinho et al., 2002; Oswald et al., 1999, 2001; Skiba et al., 2005; Sullivan & Bal, 2013) concluded that race is a significant predictor of overrepresentation even after sociodemographic indicators are introduced (Skiba et al., 2016). Morgan and his colleagues (2015) attribute the inconsistency in results to a difference in the unit of analysis used in the study. They argue that the previous studies finding race as a significant predicator of overrepresentation used district level data (Oswald et al., 1999; Skiba et al., 2005) whereby Morgan and colleagues (2015) drew from individual level data.

Who Are the Disproportionately Identified?

Evidence that is both anecdotal and empirical, has frequently reported that minority children in the United States are disproportionately overrepresented in special education (Morgan et al., 2017; Samson & Lesaux, 2009; Skiba et al., 2006; Sullivan & Bal, 2013; Zhang et al., 2014). Disproportionate identification has been found for African American children (Dunn, 1968; Morgan et al., 2017; Oswald et al., 1999; Skiba

et al, 2005; Sullivan & Bal, 2013; U.S. Department of Education, 2016a; Zhang et al., 2014), students of color in the high incidence disability categories of learning disability, intellectual disability and emotional disabilities (Donovan & Cross, 2002; Kramarczuk & Tefera, 2017; Oswald et al., 1999; Kramarczuk & Tefera, 2017) children from low SES households (Sullivan & Bal, 2013) and by third grade, children who speak a language other than English as their primary language in the home (Samson & Lesaux, 2009). African American students have a risk ratio of approximately 3.0 for identification as a student with an intellectual disability meaning that they are three times more likely to be identified as having an intellectual impairment than their White counterparts, but have a risk ratio of 0.94 for a hearing impairment and 0.84 for deaf-blindness (Skiba et al., 2008).

Skiba et al., (2006) posits that in almost all disability categories, African American students were more likely than peers with the same disability to be placed into more restrictive learning environments. Minority disproportionally in special education may suggest that students of color, particularly African Americans, may not experience the opportunity to be educated with their non-disabled peers in general education settings at the same rate as their white peers with disabilities (Skiba, et al., 2006).

Recent Reports of Minority Children Under-Identified for Special Education Services

Whether and to what extent under-identification is occurring in special education based on race and ethnicity is currently under debate (Albrecht et al., 2012; Morgan & Farkas, 2016; Morgan et al., 2016; Skiba et al., 2016). Although many previous studies (Oswald et al., 1999; Skiba et al., 2005) have found that African American students are

disproportionality overrepresented in special education, recent studies have indicated that they are less likely than their similar White peer counterparts to be referred or found eligible for special education services when compared with otherwise similar White children (Hibel et al., 2010; Morgan et al., 2012, 2015; Shifrer et al., 2011). This new research attempts to account for longstanding (Donovan & Cross, 2002; MacMillan & Reschly, 1998) and ongoing (Morgan et al., 2017) methodological limitations in previous studies by controlling for variables such as individual level academic achievement and family level economic disadvantage that may explain minority overrepresentation in special education (Morgan et al., 2017). By identifying the contrasts between similar or similarly situated children, research may better satisfy the legal and methodological conditions necessary for inferring racial discrimination (National Research Council, 2004). By doing so, this allows for research to provide a more rigorous assessment of whether minority overrepresentation is occurring because of misidentification based on ethnicity or race (U.S. Department of Education Office of Civil Rights, 2016).

Because schools use academic struggles or failure as a predictor for special education services, many argue that controlling for individual level academic achievement as necessary when investigating whether schools are over or under identifying minority children for special education services (Donovan & Cross, 2002; Hosp & Reschly, 2004; Morgan et al., 2017). For most students, academic achievement is the key variable in special education identification (Hosp & Reschly, 2004; Morgan et al., 2017) and minority students have been identified to be more likely than their White peers to struggle academically (National Center for Education Statistics, 2015). Because academic struggles tend to appear by school entry (Fryer & Levitt, 2013; Garcia, 2015),

the odds that minority children will be referred for special education services is disproportionately increased (Donovan & Cross, 2002; Hosp & Reschly, 2004). These academic struggles have been linked to greater exposure to gestational, environmental, and economic factors, including, but not limited to, low birth weight, environmental lead exposure, and poverty (Donovan & Cross, 2002; Garcia, 2015; Morsy & Rothstein, 2015).

Research that controls for children's academic achievement and other variables not specified in the literature, fails to find supporting evidence of over-identification based on ethnicity or race (Morgan et al., 2017). When these variables are accounted for, minority children are less likely to be identified as having a disability when compared to their similar White counterparts (Hibel et al., 2010; Morgan et al., 2012; Morgan et al., 2017; Morgan, Hammer, et al., 2016). However, whether and to what extent under identification based on ethnicity and race occurs in the United States is under dispute in the literature (Morgan & Farkas, 2016; Skiba et al., 2016). Described as "controversial" (Council of Exceptional Children, 2015) and dismissed as flawed (Cohen et al., 2015; Ford & Toldson, 2015; Skiba et al., 2016; Welner & Skiba, 2015), some researchers and policymakers have questioned the validity of the under identification findings (Collins et al., 2016; Skiba et al, 2016) based on race and ethnicity because the results have been based on nationally representative but smaller data sets than those used by the Office of Special Education and Rehabilitative Services (OSERS) or the U.S Department of Education Office of Civil Rights (OCR) (U.S. Department of Education, 2016; Welner & Skiba, 2015.

Research that has investigated the relationship between race and special education eligibility that controlled for individual level variables of poverty reduced but did not eliminate the significant influence of race on overrepresentation (Sullivan and Bal, 2013; Wiley et al., 2013)

Critique of the Morgan and Colleagues Research

The findings of Morgan and his colleagues' 2015 primary study indicating that there is no minority overrepresentation in special education has come under scrutiny in two primary areas: their data source and their handling of race as a variable (Collins et al., 2016; Skiba et al, 2016).

First, concerns were noted about the validity of the data source for the study's central dependent variable. Morgan and his colleagues drew their data from the 1991 ECLS-K, a national longitudinal database that focuses on early childhood experiences and how they impact school entry, transition, and progression through eighth grade. Although they used a number of variables in their analysis, the central dependent variable, service in special education, comes from an item from the ECL's supplemental Special Education Teacher/Service Provider Questionnaire where teachers were asked to identify a student's primary disability category (Skiba, et al., 2016). Concerns could be raised about the validity of the teacher's estimates from a sample of fewer than 5,000 (Skiba et al., 2016). Comparisons between Morgan et al.'s research and the data collected from the U.S. Department of Education raise concerns about the accuracy of Morgan's et al's 2015 data (Skiba et al., 2016).

Secondly, Morgan and colleagues (2015) found no evidence to support that African American children were overrepresented in any of the disability categories where

studies from the same time period (Donovan & Cross, 2002; Parrish, 2002) found significant overrepresentation of African American students in the categories of emotional disturbance, intellectual disability and learning disability (Skiba et al., 2016). In the same studies where African Americans were identified as overrepresented in special education, Native Americans were also found to be significantly overrepresented (Donovan & Cross, 2002; Parrish, 2002; Skiba et al., 2016). However, Morgan and his colleagues were unable to replicate these results in that they chose to combine Native Americans, Asian Americans, Pacific Islanders and multiracial students into one category of "Other" (Skiba et al., 2016).

Morgan et al's (2015) research brings to the forefront the question of overidentification of racial minorities in special education and challenges the current consensus that minorities are over identified. Because this study will focus on those of low income SES communities, and given that minorities comprise the majority of those in low SES communities, this study will need to be mindful to separate races and not cluster multiple racial groups into one category when reporting results. Doing so will ensure a more accurate representation of the decision making experience for parents of low SES communities and illuminate any potential patterns that may arise among racial groups.

Review of Research on Informed Decision Making

Research on Parental Experiences in the IEP Process

Unfortunately, parents of children with special needs may come to an IEP meeting and feel overwhelmed or threatened by the very team responsible for providing their child with a safe and nurturing learning environment (Wellner, 2012). Parents have

reported feeling intimidated and mistrustful of the professionals at the meeting, and question why everyone present is involved in the meeting (Smith et al, 2006). Differing perspectives and increasing types of educational intervention have led to an increase in litigation between parents of students with disabilities and schools (Wellner, 2012). For example, disagreements around eligibility, recommended services, and placement have frequently lead to litigation by parents exercising their due process rights (Katsiyannis & Herbst, 2004; Wellner, 2012).

Another challenge to effective parental involvement is an educator-dominated decision-making process (Fish, 2008; Turnbull & Turnbull, 2015). Research by Kalyanpur, Harry and Skrtic (2000), show that decisions made in the IEP meeting are more heavily influenced by the results of assessments than by a parent's anecdotal input. As a result, parents often are not active participants in their child's special education programming, but are limited to being recipients of information and signing documents (Fish, 2008). For families of low SES and those who are culturally diverse, this lack of value assigned to parental input, expands an already existing chasm to developing collaborative relationships between the school and parents (Kalyanpur et al., 2000).

Regrettably, it is common for educators to be perceived as unwilling to listen to parent input (Pruitt et al., 1998). Furthermore, certain groups of parents of children with disabilities (e.g., Mexican-American parents) are at risk of having their input devalued at IEP meetings (Salas, 2004). Parents sense these tensions, and a body of research has suggested that parents find the IEP process disconcerting (Stoner et al., 2005). This may stem from a perception of the overall process of the IEP as complicated, confusing and

traumatic (Stoner et al., 2005), or may be rooted in a specific history of negative interactions with educators at IEP meetings (Fish, 2006).

Often, educators assume that parents come to meetings prepared with enough knowledge to discuss the needs of their children (Fish, 2006, Fitzgerald & Watkins, 2006; Skinner, 1991), not realizing that parents are often reluctant to convey their lack of knowledge about special education (Fish, 2008). Parents that struggle to understand special education jargon and terminology are likely to perceive themselves as unprepared or under-prepared to discuss their children's educational needs when meeting with school officials (Fish, 2008). Parents can find themselves in meetings where they are asked to provide input, but are at a disadvantage when they lack the expertise and knowledge of the trained professionals at the table. For parents of low SES communities, they may be the least educated adult at the table. Parents who feel ill-prepared to make educational decisions for their child may be easily convinced by educators that the decision-making should be left to school personnel (Rock, 2000). Parents may feel additional pressures to rely upon the decisions of school staff if they feel that exercising their rights would negatively impact their relationship with school staff (Leiter & Wyngaarden Krauss, 2004). These findings are supported by additional research by Klinger and Harry (2006) who found that many education professionals view IEP meetings as a place to inform parents of their decisions rather than as a place to actively involve parents in the decision-making process.

Research on Parental Participation: A Special Type of Advocacy

From the moment a parent first learns of their child's disability, they are thrust into the universe of special education, a universe with its own terminology, rules, staff

and procedures. In addition to coping with the newness of their child's needs, parents are plunged into the role of becoming the principle advocate for their child. Early disability rights literature describes advocacy as the act of speaking and acting on behalf of another person or group of people to help address their preferences, needs and strengths (Wolfensberger, 1977), a definition that continues to resonate today with the IDEA and NCLB expectation of parent participation throughout the special education process. However, the expected outcome of parental advocacy – ensuring that the educational needs and rights of their child with a disability are being met – is an enormous responsibility. The participation rights and responsibilities outlined in IDEA encompass deeply embedded assumptions not only about a parents' beliefs and values but their knowledge and skill subset regarding special education and the social interactions required for advocacy (Kalyanpur et al., 2000 & Trainor, 2010). There is an assumption that the parents' prioritization and notion of normal are equivalent to those set by the dominant culture (Harry & Klingner, 2014; Kalyanpur & Harry, 1999). However, the concept of normal values and beliefs is not universal (Trainor, 2010). This lack of agreement among parents may account for variation in their approaches used when advocating for their disabled child's needs. The IEP process is where both differing experiences and perspectives are to meet to come to one unified decision. Within these differing views both parents and school personnel must determine what is in the best interests of the student to meet their academic and social needs.

Research on Barriers to Parental Advocacy

There are several issues outlined in the research that impact parental advocacy.

Although negotiating school systems is difficult for all parents, it is particularly difficult for those who are not white and not from the middle class with a college education (Connor & Cavendish, 2017; Valle & Aponte, 2002). Parents from low socioeconomic backgrounds value education similarly to the ways that their middle and upper class counterparts do, but are more likely to leave the responsibility of educational decision-making to the teachers (Horvat, Weininger, & Lareau, 2003; Lareau, 1987). Research supports four major components that contribute to parental confidence and willingness to advocate for their children: (1) creating positive relationships with teachers and professionals (Blue-Banning et al., 2004; Hess et al., 2006, Trainor 2010); (2) consistent membership on IEP teams (Park, Turnbull & Park, 2001); (3) access to information about the special education process, rights and responsibilities included in IDEA (Leiter & Krauss-Wyngaarden, 2004); and (4) language ability/barriers (Lian & Fontánez-Phelan, 2001; Trainor, 2010). It is important to note however, particularly in light of points three and four above, research by Fitzgerald and Watkins (2006) found that the readability levels of parents' rights and procedures handbooks exceeded the reading ability of many parents, creating a potential barrier to parental advocacy. Also, parents who are dominant in a language other than English may need access to bilingual information in their native language about assessments, educational approaches, special education documents and interpreters during meetings (Lian & Fontánez-Phelan, 2001; Trainor, 2010). A brief description of the readability literature follows with points to elucidate why it is important in parental advocacy.

Research on Diverse Approaches to Parental Advocacy

In 2010, Audrey Trainor conducted a study to determine the types of capital resources parents perceived as necessary to their participation in the special education process. Her participants came from diverse racial, ethnic, and socioeconomic backgrounds as well as diverse disabilities of their children. She found that some parents discussed advocating for educational systems change, but most focused their efforts advocating on behalf of their children to address individualized preferences, strengths and needs. She developed four approaches to parental advocacy based on the results of two focus groups and individual interviews. The four parental advocacy approaches that emerged included parents that acted as intuitive advocates, disability experts, strategists, and agents for systemic change. As the approaches were not mutually exclusive, some parents used multiple approaches. Table 5 provides a detailed description of each of the four types.

This research study aims to build upon Trainor's findings. The present study will focus on what Trainor identified as the "Intuitive Advocate," as this group typically has limited to no access to external resources to advocate for their children's special education needs, and are more likely to be of low SES communities given their qualification for free and reduced meals.

When considering how heuristics can be applied to the special education decision-making process for parents, consider the vignette of a parent of a fifth-grade child with an IEP advocating at the IEP meeting to have their child transferred to a self-contained special education classroom that has fewer children because the child's current classroom has too many children. The parent is

Table 5

Four Approaches to Parental Advocacy

Name	Description	Characteristics of Parent Utilizing This Approach	Noteworthy Findings
The Intuitive Advocate	- Incorporates perceptive insights parents develop through their relationships with their children - Intuitive Advocates emphasized the importance of "knowing my child" and being in the best position to understand or accurately assess their child's needs	- Utilized more by parents who were eligible for free and reduced meals (*the measurement used to determine SES*) - Few parents who used this approach gave examples of their use of additional approaches to advocacy - More commonly used amongst parents who had limited access to complex information about disability or special education	- Intuitive advocacy was not always a powerful approach. - Teachers often disregarded this type of information resulting in thwarted advocacy

The Disability Expert	- Incorporates knowledge about disabilities as they advocate. These parents have developed their expertise from sources outside of school contexts such as doctors, disability-specific organizations, commercially available texts and websites, workshops, and meeting with national experts	- Users of this strategy spanned racial, ethnic and SES backgrounds, however parents of children with autism focused on this approach	- Parents from Native American Indian, Latino, and African American (with the exception of parents of color whose children had been diagnosed with autism), noted that they thought the disability categories assigned to their children were imprecise or incorrectly assigned
The Strategist	- Combines their understanding and sense of disability and their child's unique strengths and needs with their knowledge	- Use sophisticated knowledge about IDEA, included with their understanding of special education documents,	- Strategist viewed the IEP as a record of what should be happening in school

	about special education - Strategist understand the role they potentially play in making decisions about referrals and evaluations, services and accommodations, and inclusion	procedures, and parental rights to engage in advocacy - Most are NOT eligible for free and reduced lunch - Strategist shared implicit norms and rules for communicating with teachers and administrators. Many believed that communication styles influenced the success of their advocacy	- Noted they understood the emphasis in special education process on written communication - Tended to cite legal precedence to teachers - Strategist were aware of the struggle to meet the needs of their children with the need for change in the educational system
The Change Agent	- Change Agents discuss concerns about the level of complex knowledge and social networking required to advocate for their individual child (*this*	- Parent has to understand educational systems functions as well as special education specific knowledge - NONE were eligible	- Access to economic resources is an integral component for the systems change approach

	is what motivates them for systemic change)	for free and reduced lunch	-	This type of advocacy required investments of time to establish relationships

concerned that their child is not getting the attention they need and is concerned that another child is causing too much disruption in the classroom as they have done in previous years. The parent's rationale is that the child would perform better in a classroom with fewer students. The parent has observed such a classroom in the building and wants their child moved to that classroom. The parent notes that the classroom has half as many students and there are two adults in the classroom and that such a small student ratio is what their child needs to focus and be successful in class. Other parents at the school are complaining about class size noting that there are too many children in the classrooms.

In such a scenario, it may be true that the student would do better in a smaller class; however, so would most students, regardless of whether or not they had an IEP. Unknown to this parent is that self-contained classrooms for students in special education tend to be program specific and for students with more significant delays that cannot be addressed through inclusion or resource-based programs. Students in self-contained classrooms tend to have more significant needs educationally. If the parent is unaware of the different types of special education supports and/or is unable to seek out information about other options, using the information that is available about their child's current

school will be deemed sufficient for making their conclusion that the smaller classroom is appropriate for their child. The availability heuristic has been utilized when the parent assesses the risks of switching the child's class based on hearing that another student is difficult to manage in the current classroom and having not heard of any behavior problems in the other classroom. The availability of information about one classroom may lead to an assessment of risk that is inaccurate and the parent's attempts to find other ways to keep their child enrolled in the general education classroom may be reduced. Thus, the availability heuristic suggests that one way in which individuals simplify the decision-making process is by giving greater consideration to the information that is available – that is, the information that can be mentally accessed easily, either because it has been experienced frequently, is salient, or has been recently encountered (Chaudry et al., 2010).

Research on Readability: Why it Matters

From the moment a child with a disability is diagnosed, parents are bombarded with written documents from hospitals, government agencies, service providers and schools. To ensure that families can be involved in each stage of their child's life, the readability of these documents is important. Readability, or the ease of reading and understanding a piece of writing, which focuses on words and sentences, is a critical component in the use of written communication (Lo, 2014). However, perhaps the most comprehensive definition of readability comes from Dale and Chall (1948) as they describe readability as all of the interactions that affect the successful use of the material, including the ability to understand the imparted information, read the information at an optimal speed, and find the information of interest (Dale & Chall,

1948). When going through the special education process, a common and critical piece of literature given to parents is the Parent's Rights and Procedural Safeguards Manual. This document is required under Title IB part 612a6 of IDEA 2004 to be given minimally once a year to families. It details the procedures of the special education process as well as a parents' rights under the law as they proceed through the special education process. Important information, such as what to do if you disagree with the team's decision or how to obtain a free independent evaluation, are included in the manuals. As each state creates its own manuals, the readability of the manuals varies from one state to another.

To ensure that parents are involved in each step in the development of their child's special education plan, multiple components have been added as a part of parents' rights in the amended IDEA of 2004. For example, all communication must be provided in the parent's native language, schools must follow specific timelines to ensure that parents receive information within a timely manner throughout the process, parents must be included in the decision-making process, such as parental consent must be obtained prior to evaluating a student, and parents must be included on the IEP team (Lo, 2014).

A review of the literature on readability levels is sparse, but important enough to resurface every few years. In the readability literature written from 1984 to 2019, the recommended appropriate readability level steadily decreased every few years, with early recommendations being no higher than ninth grade (Roit & Pfol, 1984) but suggested at a fifth-grade level as of 2014 (Lo, 2014). In 2006, researchers noted that there was no consensus on what constituted an appropriate adult readability level, but concluded parental written communication should be ideally written at a fifth or sixth grade reading

level unless technical terms were used (Fitzgerald & Watkins, 2006; Nagaro & Stein, 2016; Pizur-Barnekow et al., 2010). In such an instance, the readability level should not exceed the seventh or eighth grade (Fitzgerald & Watkins, 2006). Research from 2010 supported the findings that a fifth-grade reading level was appropriate for parents, including those living at or below the poverty level (Pizur-Barnekow, et al 2010). Similarly, in 2014, a fifth-grade reading level continued to be considered an appropriate readability level when corresponding in writing with parents due to many parents reading up to six grade levels lower than their highest grade of completed formal education (Lo, 2014; Pizur-Barekow et al., 2010; Roit & Pfol, 1984). As of 2019, no procedural safeguards manuals scored below an 11th grade reading level (Gray & Atcherson, 2019). Seventy-four percent of those examined were found to be written at a graduate reading level (Gray & Atcherson, 2019). This means that they are written for readers currently enrolled in a master degree or higher education program.

There are significant challenges if a document is written at a tenth-grade reading level; primarily that the parent would need to be at a tenth-grade reading level to comprehend the document. However, for many parents of low SES communities, their education level may not match their actual reading level (Fujiura & Yamaki, 2000; Grotlüschen et al., 2016). Furthermore, parents of children with disabilities may be more likely than other parents to experience difficulty with reading (Fitzgerald & Watkins, 2006; Lo, 2014) as genetic links have been discovered for learning disabilities, mental retardation, dyslexia and other disabilities (Fitzgerald & Watkins, 2006). Evidence from longitudinal studies of students with disabilities suggests that parents of children with

disabilities who are most vulnerable to poor educational and social outcomes are those that come from disadvantaged backgrounds (Mandic et al., 2012).

Most procedural safeguard manuals, a manual required in each state to be provided to parents in the special education process that details their rights under the law, are written using legal jargon and assume the parent/guardian has the ability to read and comprehend complex language, policy, and navigate the school system. Figure 3 illustrates the various features needed to create a document with high readability (easy to read) versus that of low readability (difficult to read). Because many of the poorest individuals in our society are often our least educated, they are unable to access information in the same manner as their educated, affluent counterparts. Policies, such as those normalizing the use of print culture in school systems, perpetuate systems in which the poorest members of society are disenfranchised and disadvantaged. The chronically poor, those that have experienced poverty for long periods of time - five years or more - or possibly all of their lives, are more likely to be neglected given the multitude of factors that impact their ability to change their economic status and contributing to both continued economic and education deprivation (Hulme & Shepherd, 2003). Pressures to view those of low socioeconomic status means as a homogeneous group also distorts policy and weakens its analysis (Hulme & Shepherd, 2003).

Research on Oral Culture Versus Print Culture

In an effort to advocate for the needs of their children, parents of children with disabilities have to be able to successfully navigate school systems. To be successful in navigating the world of education, families of lower SES communities have to overcome at least two main obstacles: first, learning the language of the middle class (Beegle, 2003;

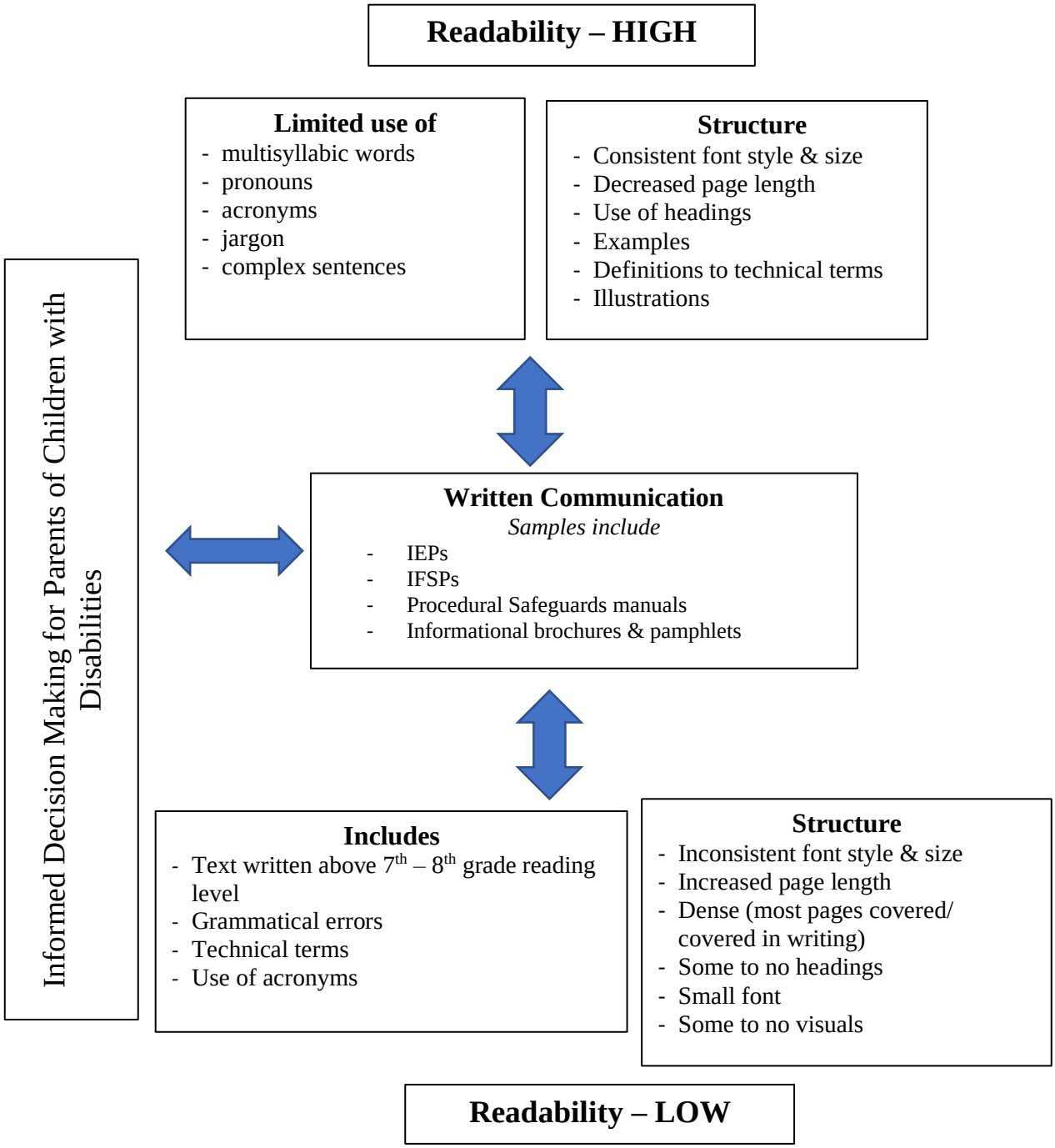
Ong, 1982), and second, learning the communication styles of the middle class, as both are the dominant language of school systems (Beegle, 2003; Ong, 1982). Research by Walter Ong (1982; 2013) found that most people living in poverty demonstrate characteristics of *oral culture* through which they obtain information primarily verbally (Ong, 1982). Ong describes oral culture as being spontaneous, relationship-based, and strongly associated with emotions and physical touch. When talking, verbal communication may not necessarily focus on one idea, but may bounce from one idea to another (Beegle, 2003; Ong, 1982). Those who obtain their information primarily from print demonstrate characteristics of *print culture* and tend to be individualistic, linear, analytical and focused (Beegle, 2003, Ong, 1982;). Current U.S. educational systems are designed for those who obtain information through print culture. When parents and students of lower SES communities enter the world of education, there is often a mismatch in communication styles, as individuals with lower levels of education and use of oral culture encounter the formal style of print culture prevalent in the U.S. education system (Beegle, 2003).

Chapter Summary

Parents who have a child with a disability are routinely required to make multiple decisions about their child's special education needs. Parents are expected to be active participants in the processes of assessing, planning, and developing their child's eligibility determination for special education services and developing their child's Individual Education Plan (IDEA, 2004). For parents to make informed decisions about their child's education, they must be familiar with the various complexities of the law and their rights under the law. Ensuring that parents are well informed and involved in their

Figure 3

Features of High and Low Readability Documents



Source: *Atcherson et al, 2013; Fitzgerald & Watkins, 2006; Lo, 2014*

child's education is at the heart of special education policy. Many parents of students with disabilities find understanding special education materials and regulations daunting when considering not only the volume of information given to them, but also the inclusion of legal jargon and technical terminology (Burke, 2013). This is compounded when parents are undereducated or their reading levels do not match their educational levels (Nagaro & Stein, 2016). Further compounding these challenges are the effects of poverty. Given that parents from lower SES communities have poor information search strategies and are isolated from social networks – one of the most efficient ways parents from higher SES communities learn information (Schneider et al., 2000), how do parents from a low SES community gain the information they need to make an informed decision? The purpose of this phenomenological study is to determine how the experiences of socioeconomically disadvantaged parents of children with disabilities make decisions about the special education needs of their children.

Research on parental participation in the special education process focuses on establishing collaborative relationships, increasing parental involvement in schools, the benefits of parental involvement on student performance and ways to predict parental involvement. However, there is limited information on how parents of low SES communities make decisions about their child's educational needs. It is hoped that this study will contribute to the research on parent involvement in special education by examining the advocacy experiences of parents of children with disabilities and providing a perspective that will enable educators to focus on the needs of parents in low SES communities while understanding the barriers they face when advocating for the needs of their children in school.

Chapter Two provides a full and detailed description of the rationale behind the selection of the Heuristics and Biases Framework and how subjective construal and

cognitive bias relates to studying how parents of low SES communities make decisions about the needs of their children with special needs. Chapter Two also details justification for this study based on the gaps in the literature about understanding the decision making process for this specific community and its desire to build upon the research of Audrey Trainor.

CHAPTER THREE: METHODOLOGY

Qualitative research methodologies collect open ended data that can be used to develop themes (Creswell, 2003). Such methods are useful when research seeks to understand meanings, look at, describe and understand experiences, beliefs, ideas, or values. Because qualitative methodologies support studies that are exploratory in nature, the use of qualitative methodology can indicate that there is not much written about the participants or the topic of the study (Campbell, 2014; Creswell, 2017).

Examples of qualitative methodologies include ethnography, grounded theory, case study and phenomenology. Ethnography relies on direct observation and researcher perspective (Padgtt, 2016). Ethnography allows a researcher to collect data by observing members of a cultural group in their natural environment over a period of time (Campbell, 2014; Creswell, 2017). In grounded theory, researchers formulate theories related to process, action or interactions rooted in their participant's responses and reactions (Campbell, 2014; Creswell, 2017). Case studies draw on the researchers ability to extract depth and meaning in context as they explore in detail an event, an activity or a process of one or more individuals (Campbell, 2014; Creswell, 2017; Padgett, 2016). Research that focuses on the lived experiences of individuals is the foundation of phenomenological research. This study will focus on the lived experience of parents of

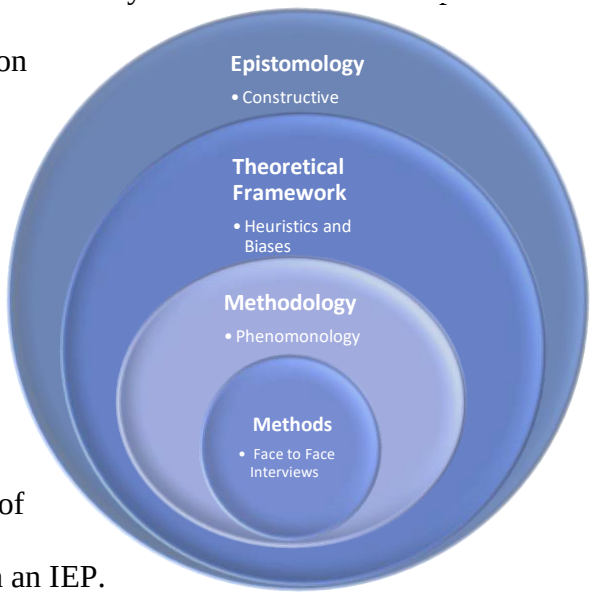
low SES communities as they make decisions for their children with special needs. Because this study is interested in finding common themes amongst a population's experiences, phenomenology is the most appropriate qualitative methodology for this study.

The purpose of this study is to: (1) understand the decision making experiences of parents of low SES communities about their children's special education needs; (2) give parents of low SES communities with a child with special needs an opportunity to share their perceptions of navigating the special education process; and (3) to provide recommendations for policies and practices to better inform parents so they can make informed decisions about their child's needs. The following research questions will guide this study and were used as a guide to create the interview protocol:

1. How do parents from low SES communities experience their child's disability?
2. What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?
3. How do parents from low SES communities interpret their rights and responsibilities in the educational process?
4. How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?

Epistemology

Figure 4
Epistemology



The purpose of identifying an epistemology for a study is the philosophical position about knowledge, upon which the study will be based upon (Creswell, 2007). An epistemology explains the decisions made throughout the study (Creswell, 2007). This study, through the use of a basic qualitative design aims to fill a gap in the literature by providing a voice to parents of low income communities who have a child with an IEP.

This qualitative study as shown in Figure 4 will be viewed through a constructive epistemological lens (Vygotsky, 1964). Constructivism is an epistemology that is a set of beliefs about the nature and origin of knowledge (Meltzer & Reid, 1994; Vygotsky, 1964). It theorizes that real understanding is constructed based on an individual's previous experience and background knowledge (von Glasersfeld, 1995; Ultanir, 2012). This lens will support the heuristics and biases framework in that a constructivist lens maintains that individuals create their own understanding through their interaction of what they already believe and the events or activities they experience (Ultanir, 2012; Vygotsky, 1964). A constructivist lens will assist in understanding the lived decision-making processes experienced by parents of low SES communities who have a child with an IEP as they go through the special education process. The constructivist lens will also assist in understanding the interaction between the parents' knowledge bases, such as their procedural knowledge, strategies, skills and the application of such knowledge to the decision making experience around their child's special education needs. The goal of

examining this phenomena through this lens would be to determine what parents know and can know with support.

Given the intricate amount of knowledge needed to make informed decisions about their child's special education needs, a parent needs to be not only well informed of their options, but also able to navigate through the multiple options to obtain a conclusion they deem appropriate for their child's best interest. This study posits that parents of low SES communities are not accessing the written communications that detail their rights throughout the special education process. Given this assertation, parents of low SES communities are accessing information through other means, most likely through others in their trusted community. The question is who comprises this community to aide them in their decision making. The research questions in this study will seek to determine not only how parents use information to make decisions about their children's needs, but also where they obtain information.

The heuristics and biases framework will be used to understand how parents of low SES communities both receive and process information under conditions of uncertainty, ambiguity or in the face of complex or incomplete information. By examining construals (how individuals perceive, comprehend and interpret the world around them) and the heuristic process (strategies an individual uses to makes a decision about something in which they are unfamiliar, complex, or when the individual has little practice in making such a decision), this study seeks to understand how parents of low SES communities make decisions about their child's special education needs.

Phenomenology

Historical Review of Phenomenology

Phenomenology is a philosophy of experience. For phenomenologists, the ultimate source of all meaning is the lived experience of human beings. Throughout the years, the leaders of phenomenology have debated how the lived experience translates into the foundation of knowledge (Armstong, 2005). Modern phenomenology of the late twentieth-century contained central themes of language such as how literary works are understood differently by audiences with different interpretive understandings (such as the works of Hans Robert Jauss and Wolfgang Iser) and the interpretation of an experience (Armstong, 2005). The modern founders of phenomenology, Edmund Husserl and Martin Heidegger (Padgett, 2016) although disagreed on some aspects of phenomenology, agreed that in order to gain knowledge of the world, one must examine experience (Armstrong, 2005). To do this, one must avoid all preconceptions to their understanding of experience, (i.e. scientific, historical, aesthetic). Contemporary phenomenology has mostly abandoned Husserl's dream of finding indisputable foundations of knowledge. Contemporary phenomenologists Hans-Georg Gadamer, notes that although some prejudices may be misleading, oppressive or constricting, understanding is impossible without prejudgments provided by cultural norms and inherited beliefs (Armstrong, 2005). Largely due to the work of Gadamer, hermeneutic phenomenology and reader response theory, two branches of phenomenology, have been heavily influenced to focus on the role of customs and presuppositions in the human participant and that human's understanding of the world. (Armstrong, 2005). The late twentieth-century phenomenologist stress the inherent enmeshment of experience in cultural traditions, history and language (Armstrong, 2005).

Description of Phenomenology

In line with the principles of qualitative research, this study will utilize a transcendental phenomenological approach (Moustakas, 1994) to assist in understanding the lived decision-making processes experienced by parents of low SES communities that have a child or children with an IEP. Similar to phenomenological research, transcendental phenomenology is used to describe "what all participants have in common as they experience a phenomenon" (Creswell, Hanson, Plano & Morales, 2007, p. 252). A phenomenological study explores the meaning for several individuals of their lived experiences of a concept or a phenomenon (Creswell, 2007). This means that phenomenology focuses on describing a phenomenon that all of the participants have experienced.

Research Design

Appropriateness of Phenomenology for this Study

Phenomenology provides the framework for this study as phenomenological approaches are distinctively suited to illuminate the meaning of an experience for parents of low SES communities as they go through the special education process and make decisions for their children's special education needs. Phenomenology will allow us to identify a phenomena through how it is perceived by the parents living the experience as phenomenology is concerned with the study of an experience from the perspective of the individual. A phenomenological analysis of the data collected will explore not only what parents have experienced but also the conditions and situations surrounding those experiences.

Based on the work of van Manen (2002), "hermeneutic phenomenology" will be useful as it involves the analysis of texts that describe the phenomenon or experience,

which in this study will include a review of interview transcripts and other written materials such as the procedural safeguard manuals. Other phenomenological analysis' will be based off of the work of Moustakas (1994) who follows a "transcendental" phenomenological approach. In this phenomenological analysis the researcher brackets or sidelines their preconceptions about what is real (Moustakas, 1994; Padgett, 2016). This means that the researcher is not entirely absent from the study, but attempts to make a deliberate effort to be self-aware enough as not to intrude on the essential aspects of the participants accounts. For this study, given my extensive experience in holding meetings with parents of low SES communities, bracketing will be an essential component to ensure that I do not superimpose either of my own presuppositions or assumptions based on my own previous experiences. Because phenomenological approaches are based in a paradigm of subjectivity and personal knowledge, and emphasize the importance of personal perspective and interpretation, they are an appropriate method for understanding subjective experiences and gaining insights into an individual's motivations and actions (Lester, 1999).

The use of a qualitative research design in this study provided insight into the phenomena of the lived experiences of parents of low SES communities who have children with disabilities and how they gain and use information to make decisions about their child's special education needs. The design of this study allows the engagement of parents in the study and provides them with the opportunity to share their own thoughts on the parental decision making phenomenon based on their own experiences. Phenomenological interviews revealing low SES parental experiences may be advantageous because a phenomenological inquiry could allow for a deep understanding

of the experiences of parents of low SES communities, while determining the needs of their children with special needs. Van Manen (2007), argues that phenomenological research aims at creating formative relations between acting and being, between how we act and who we are, as well as between tact and thoughtfulness (Shi, 2011). Research using the phenomenological framework is "always to question the way we experience the world, to want to know the world in which we live as human beings" (van Manen, 1990, p.5).

Foreshadowed Problems

Potential problems may fall into two categories: fundamental and situational (Shi, 2011). Fundamental problems refer to problems that arise from using phenomenology as a research method. Fundamental problems can include objective versus subjective dilemmas when interpreting data and quandaries regarding participant voice versus researcher voice. Situational problems refer to dilemmas that are situation specific such as differences in language and culture, and parental recruitment. Detailed descriptions of each potential dilemma in this study follow below.

Fundamental Dilemma: Objective Versus Subjective

A question that surrounds phenomenological inquiry is whether the process is objective or subjective. Specifically, can the researcher avoid imposing personal experiences and biases on the description or analysis of the experiences shared by the participants? In this study, I will already assume that parents are not reading the procedural safeguards manuals. How does my analysis of the results change if I find that parents are reading the safeguards manual? To combat unforeseen challenges with such a preconception, this researcher bias must always be at the forefront of my mind when

interpreting the data. I will also need to develop a separate line of inquiry for parents that read the manual to determine how the manual assists them in their decision-making.

Fundamental Dilemma: Participant Voice Versus Researcher Voice

Van Manen (1990) noted that the act of research itself is a caring act because the value of the research is in knowing the essence of a human phenomenon. He argued that in orienting oneself to a phenomenon, one will always imply a particular interest. However, the reverse can also be said to be true – that we can only understand a phenomena about which we care (Binswanger, 1968). In conducting a phenomenological inquiry, the researcher must ask his or herself if they are speaking for themselves or the participants when conducting and reporting on phenomenological research. To avoid this dilemma, I will always need to be cognizant of whose perspective an inquiry will be based. This becomes paramount when taking into consideration that I have worked in special education for over eighteen years with parents of low SES communities.

Throughout this study, multiple revealing insights might be gained, however these insights might become integrated with my own background and experiences. It is possible that in interpreting data, I may end up speaking through my own perspective rather than through the parent's perspective. As the analyzer of the data, it will be paramount to always ask myself if I am speaking adequately and authentically for a population of whom I am not a member. For example, the participants in this study will be parents of low income whom have a child with a disability, potentially limited educationally, and have access to fewer resources. I, on the other hand am not of low SES, pursuing a fourth college degree and have access to a multitude of resources. Although I come from a single parent home and understand the need for a budget, at no

time in my upbringing did I identify as disadvantaged. Although my mother has a disability that I have had to make decisions about since high school, I have always had access to resources such as additional family members, research, the internet and professionals for any questions. If I am neither poor, nor an uneducated decision-maker, this leads to the dilemma of to what extent am I privileged about the content? As an educator and administrator who has talked parents of low SES communities through numerous IEP team meetings, whose experience am I exploring – the parent whom is interviewed or the educator who serves the parent and their child – as these roles are closely related in the special education process, particularly when sitting at a meeting together?

Situational Dilemma: Cultural and Language Differences

As this study sought to explore the experience of parents from low income communities in the special education process, it did not explicitly seek to explore the experience of native English speaking parents as a pre-requisite to participate in the study, thus a participant did not have to be a native speaker of the English language to participate. This study did not presume that the experience of uninformed decision making differed due to language, but may have been exacerbated due to a language barrier. However, being a non-native speaker of English can introduce a new problem if an interpreter is unavailable. It can be difficult to conduct an in-depth interview about a parent's lived experience if the parent has limited English proficiency. Ideally, in an interview, the parent will do most of the talking which may prove difficult for a parent with limited English proficiency. Even if the transcript of the interview is read back to the parent, it will be difficult to determine if the parent understands the content of the

transcript, thus impacting validity of the results. To address this challenge, participants will need to be moderately proficient in the English language as all interviews will be conducted in English due to a limited amount of translators available.

Culturally, the background of a researcher can play an important role in phenomenological interviews (Hofstede, 1984). Of the four dimensions of culture identified by Hofstede (1984), "uncertainty avoidance*"* is perhaps the most detrimental to this study as parents and places such as schools and organizations utilized to recruit parents to interview may be uncomfortable with the uncertainty of what happens not only in a research study, but also with the information garnered in the study. Uncertainty avoidance is a cultural quality that refers to the extent to which individuals of that culture attempt to minimize uncertainty (Shi, 2011). Uncertainty avoidance is a society's ability to tolerate uncertainty and ambiguity. If the participants in the study perceive this researcher as an outsider of means that they do not possess (i.e. financial, educational, social, cultural) it is possible that they will view the relationship between the researcher and the participant as a hierarchical structure. In strict hierarchal power structures, those that are at the bottom are unlikely to question authority. In cultures with high uncertainty avoidance, teachers are viewed as having all the answers and learning is structured. In cultures with low uncertainty avoidance, teachers are not necessarily viewed as all-knowing and the learning is open minded with less focus on facts (Shi, 2011). Such a perception could have impacted a participant's responses if they attempted to answer questions based on what they thought the researcher was looking to find. To combat this dilemma, participants were informed at the onset that this research sought to determine how parents used information to make decisions about their child's special education

needs. By providing clearly defined roles, less uncertainty was experienced by the participants.

Additional uncertainties that factored into this study included if organizations were uncertain of how the information obtained through the interview process would be used, they were less willing to introduce me to their parent population, particularly because special education and free and reduced populations are protected populations. If participants were uncertain about the use of their information, they may have be less likely to be forthcoming in their responses in an effort to protect that which they felt was confidential. To combat this dilemma, I informed all parties that any identifiable information such as the name of a school, child or any individual mentioned by name would be removed from any written transcripts and findings. A finalized, redacted (with identifiable information removed) copy of the interview was provided to the participants and read aloud to them if needed.

Situational Dilemma: Parental Recruitment

Potential problems for this study included the use of parent volunteers for interviews. By relying on volunteers, it is possible that the results are reflective of a subgroup within a subgroup, specifically those who are willing to interact with a researcher, or those that have the capability to interact due to issues with other competing priorities, narrowing the global applicability of the results. Since parents could only be recruited voluntarily, and could not be compelled to be interviewed, it was noted as a potential limitation of the study in the conclusion.

Additional potential problems to this study included the recruitment of participants. Identifying parents willing to participate in the study that were

available to interview for an hour might was projected as a potential obstacle given parent's competing priorities. Every effort was given to meet at a time and location that was convenient for parents to attend the interview for the study. Parents were offered the opportunity to meet over multiple times if preferred.

Additional foreshadowed problems included parents keeping to the scheduled meeting time. Parents may have agreed to meet but then not show for the interview or cancel. When this occurred, attempts were made to reschedule the interview; however, after two failed attempts to show, the parent was not rescheduled for the interview. Reminder phone calls, texts, and emails were sent to the parent prior to the interview date to confirm their attendance. If the parent was referred to the study through a school or community liaison, reminders were sent through them as well.

Research Questions

This study included individual interviews designed to explore parents' experiences regarding their understanding of the special education process and where/with whom they sought out assistance when uncertain about what to do in the process. Data collection took place through in-depth individual interviews (Creswell, 2007). The following research questions guided the inquiry:

1. How do parents of low SES communities experience their child's disability?

2. What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?

3. How do parents from low SES communities interpret their rights and responsibilities in the educational process?

4. How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?

Appendix C contains the interview protocol that was used for the interviews. The parental interviews contained questions that required parents to answer questions about the following themes.

- Knowledge of child's disability
- Procedural safeguards manuals
- Knowledge level of special education law
- How/where they seek out answers when uncertain about something pertaining to their child's IEP
- Recommended areas for improvement

Participants and Setting

Participants

Because the study focused on identifying information used to inform a decision of how parents of low SES communities who have a child with a disability, make informed decisions about their child's special education needs, participants had to meet the following criteria:

1. FARM (free and reduced meals) – students of interviewed parents qualified for free and reduced meals at their school as this was used as a socioeconomic indicator

2. Participants had to be the parent or guardian and be the educational decision maker for a child currently receiving special education services
3. Participants had a child with a current IEP or IFSP
4. Parents were fluent English speakers.

Participants were recruited through flyers at schools, hospitals, public service agencies, retail businesses, nonprofit organizations, and shelters. Messages were posted to disability-related list serve support groups as service providers and community members might have able to refer parents to the study. Additional resources for participants came from meeting with community leaders, district personnel (i.e. social workers, special population liaisons) to ask them to inform parents about the study. Participants received a $10 grocery gift card for participating in the study.

Potential challenges to the study included the recruitment of parents, ensuring parents showed for their interviews, language barriers for non-native English speakers and cultural barriers.

Sampling

This study utilized two sampling methods: snowball sampling also known as network sampling (Merriam & Tisdell, 2016) as its primary method and maximum variation as its secondary method. Snowball sampling is non-probability technique that is appropriate to utilize in research when the members of a population are difficult to locate (Crosman, 2015). Snowball sampling allows the researcher to ask early participants to refer them to other participants (Merriam & Tisdell, 2016). For this study, the sampling began with key members of the special education community

(coordinators, case workers, therapists, school administrators) that served parents of children with disabilities that met the criteria for the study. Once participants were identified, recommendations were asked of them for additional parents whom may have wanted to participate in the study.

Patton (2015) notes that maximum variation sampling turns the difficulty of achieving heterogeneity in small samples due to the cases being so different from one another into a strength through the following logic - "any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared dimensions of a setting or phenomenon (Patton, 2015, p.283). Maximum variation is achieved by creating criteria in advance that distinguish the sites or participants (Creswell, 2013). For this study, the researcher began by identifying potential locations for participants (schools with large FARM populations, diagnostic testing centers, child care centers) in an effort to identify the potential population to assess the maximum range of people and sites that can constitute the population (Seidman, 2013). The goal was to identify participants whose only shared commonality is that they were from low SES communities to determine if the experience is the same across parents from low SES communities rather than speaking with those from the same community (i.e. the same school or neighborhood) as any commonalities identified could be due to a common experience with the same individuals in a particular setting rather than commonalities across the sociodemographic group.

Data Collection

Semi-structured one-on-one interviews were conducted in private settings. The interviews were scheduled at an agreed upon time and location between the researcher and the participant. The interview protocol (Appendix C) was used as a guide for the

interviews to ensure consistency across interviews. Interviews were recorded using a voice recorder. Memos were used to record anecdotal notes such as body language, facial expressions and any other observations that could not be captured in an audio recording. Pauses and body language were added to the transcription of the interview to allow the transcription to recreate the verbal and nonverbal aspects of the interview (Seidman, 2013). This strategy is helpful to researchers when they are reviewing interviews months after the interview occurred (Seidman, 2013).

Interviews were appropriate for this study as this study aimed to understand the experiences of parents of low SES communities as they navigated the special education process to make informed decisions for their children. Vygotsky (1987) wrote that "every word that people use in telling their stories is a microcosm of their consciousness" (Vygotsky, 1987, pp. 236-237). By examining an individual's consciousness, researchers are given access to the most complicated educational and social issues that are constructs based on the concrete experiences of that individual (Seidman, 2013).

Prior to the interview, demographic information (name, services child receives, salary, number of people supported on the salary, disability of the child) was collected to determine if the parents qualified for the study. This aided the researcher during data analysis to determine if there was any overlap in sub demographics (i.e. racial, economic – such as different levels of poverty, disability of the child). Also prior to the interview, the purpose of the study was explained to parents and any questions from the parents were answered. Permission was asked to record the interview, however when a parent refused to have part of the interview recorded, hand written notes were taken. Pseudonyms were used in all transcripts to protect the identity of all individuals

referenced in the interviews, and to ensure confidentiality of all participants (Miles et al., 2014). Time was allotted at the end of each interview for any questions participants may wanted to address.

Development of Interview Protocol

An interview protocol (Appendix C) was developed to assist the semi-structured interviews. The purpose of the interview protocol is to understand the decision making experience of parents from low income communities as they make decisions about their child's special education needs. The questions include a mixture of open ended and topic specific questions to gather information around the following themes:

- Knowledge of child's disability
- Procedural safeguards manuals
- Knowledge level of special education law
- How/where they seek out answers when uncertain about something pertaining to their child's IEP
- Recommended areas for improvement

Table 6 displays the four research questions used to guide this study and the questions in the protocol that address each research question.

Table 6

Research Questions Guiding The Study

Research Questions	Interview Questions
Research Question 1: **How do parents from low SES communities make meaning of their**	1. How many children do you have that are receiving special education services?

child's disability?	2. How long has your child(ren) been receiving special education services? 3. What is your child(s) disability? 4. Can you describe what a _____ is? (the blank will be filled in with their child's disability 5. How does this impact their learning? 6. Do you feel that this disability describes your child (ren) correctly? 7. How do you feel about your child's academic future in school?
Research Question 2: **What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?**	1. Describe how you feel as a parent of a child with a disability when sitting in a school meeting. 2. Have you ever had a time when you disagreed with the special education team? What happened? a) Where you satisfied with the outcome? 3. Have you ever had a time when you did not speak up when you disagreed with something? Potential follow up: what kept you

	from speaking up
Research Question 3**:** **How do parents from low SES communities interpret their rights and responsibilities in the educational process?**	1. What can you tell me about this document (referring to the procedures manual) 2. Have you ever used it to find an answer to a question? What if yes. Why not if no. 3. When you are sitting in meetings, what do you wish you knew more about? 4. Have you ever had a time when you did not speak up when you disagreed with something? a) Potential follow up: what kept you from speaking up
Research Question 4: **How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?**	1. If you disagreed with something in your child's IEP or evaluation, what would you do? 2. How would you describe the experience of getting answers for your questions about your child when you aren't sure about something? 3. Have you ever had a time when you

	disagreed with the special education team? What happened? 4. Have you ever not spoken up because of fear of retaliation from the school? 5. Do you know anyone who is receiving special education services

Pilot testing was conducted with the questions before formal data was collected. This allowed the researcher to revise ambiguities in the questions as needed as well as to anticipate how participants would best understand questions (Maxwell, 2013). Piloting the questions also allowed me to determine if the questions asked garnered response that answered the research questions the study sought to answer.

Interview Procedures

Participants were invited to meet at a neutral location of their choosing that was not their home such as a school, local library, or community center. Prior to inviting a parent to the interview, it was determined through a pre-interview screening if they met the participant criteria through a series of questions:

1. Does your child have an IEP or IFSP?
2. What services does your child receive? (This question helped to assist in ensuring that the child had an IEP. A parent that was unable to describe the services their child received was not used in the study as it could not be corroborated the child had an IEP)
3. (If enrolled in school), does your child qualify for free and reduced lunch?
4. What is your current yearly salary?

a. How many people do you support on this salary

Once in the interview, participants were reminded that the interview would be recorded and that a transcript would be created with all of their identifying information removed. A written copy was provided to each participant.

Data Analysis and Management

Data Analysis

Based on research by Seidman (2013) and Saldaña (2016) there are three fundamental steps when beginning to analyze research data that were utilized in the data this analysis.

1) Reducing data – reviewing the interview and reducing interview data to what the researcher considered important. The first step in reducing the text was to read and mark meaningful passages with brackets (Seidman, 2013). Reducing the data was the first step in allowing the researcher to present the interview material and then analyze and interpret the material (Seidman, 2013; Wolcott, 1994).
2) Labeling – labeling important excerpts in categories either to develop a participant profile or to explore those passages that may be imbedded into the excerpts. Initial labeling began by exploring the following questions:
    i. What do parents of low SES communities know about their child's disability?
    ii. How do parents of low SES communities interact with the Parents Rights and Procedures Manual?
    iii. What do parents of low SES communities know about special education law?

iv. How, where or to whom do parents of low SES communities reach out when they are uncertain or do not understand something pertaining to their child's special education needs?

v. When advocating for their child with a disability, what types of resources do parents utilize?

Once individual passages were marked and grouped into categories, I studied the categories for thematic connections within and amongst them (Seidman, 2013).

A more conventional method of presenting and analyzing interview data was to organize excerpts from the interview transcripts into categories (Seidman, 2013). By searching for connected threads and patterns amongst the excerpts within their categories I was able to identify other categories that were turned into themes (Seidmen, 2013).

In this phase, Saldaña (2016) encourages researchers to "codify" the research. To codify is when the researcher arranges information into a systemic order to make it a part of a category or classification. During this process, codes were applied and reapplied to the data so that the data could be divided, grouped, reorganized and linked in an effort to consolidate meaning (Saldaña, 2016).

3) Sorting the labeled excerpts into files that were easily identifiable and retrievable for the study. The process of noting what was interesting, labeling it and sorting it into categories is called "classifying" (Seidman, 2013), "coding" (Dey, 1993, p.58) or Synthesis (Saldaña , 2016). After reading the marked passages from two to three interviews, I assessed if they could be labeled by asking myself questions such as what is the subject of the passages, are there words in the passages that suggest a category where the passage might fit, and are there words or phrases that describe the

passage (Seidman, 2013)?

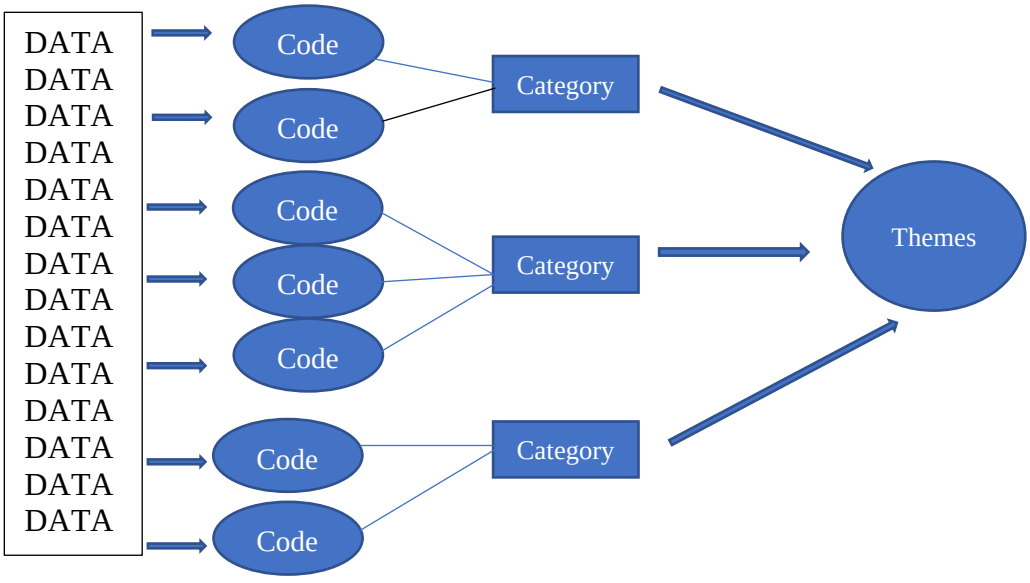
The overall process of analyzing the data will resemble a diagram designed by Saldaña (2016) in Figure 5.

Trustworthiness and Reliability

Lincoln and Guba (1986), state that the trustworthiness of a research study is important to evaluating its worth. They note that establishing trustworthiness involves the following: 1) credibility – confidence in the truth of the findings; 2) transferability – exhibiting that the findings can be applied towards other contexts; 3) dependability – showing that the findings are consistent and replicable; and 4) confirmability – the extent to which the findings of the study are shaped by the participants and not through researcher bias, interest or motivation.

Figure 5

Coding Process Used For The Study



In an effort to establish trustworthiness, this researcher utilized recommendations established by Lincoln and Guba and reiterated by Merriam and Tisdell (2016):

prolonged engagement, peer debriefing and member checks. Prolonged engagement is where the researcher spends an adequate amount of time observing various aspects of a setting, speaking with numerous participants, and developing a rapport with the members of the culture (i.e. parents in low income communities).

Peer debriefing as described by Lincoln and Guba (1986) is "exposing oneself to a disinterested peer in a manner paralleling analytical sessions and for the purpose of exploring aspects on the inquiry that might otherwise remain only implicit within the inquirer's mind (p. 308)." This researcher identified professional peers to discuss the nature of the research with and had them provide honest feedback about the study.

Peer review was also utilized throughout the data collection process as this researcher presented information to the dissertation committee to solicit their feedback and guidance to ensure that subjectivity was appropriately monitored and gathered.

Transferability was achieved through the use of rich, thick descriptive data. The researcher described the data in detail by including direct quotations from participants where appropriate. This allowed others to also evaluate the extent to which the conclusions drawn were transferrable to other times, settings, people and situations (Creswell, 2017; Seidman, 2013). The dissertation committee also served as a part of an external audit to ensure dependability and conformability. As external auditors, the dissertation committee ensured the validity, accuracy, findings, interpretations and conclusions. The use of an external audit was beneficial as it included utilizing researchers that were not involved in the research process to examine both the process and the product of the research study. The purpose of the external audit was to evaluate the accuracy and to evaluate whether the findings, interpretations and conclusions were supported by the data gathered.

Member checks included asking parents to review the transcribed interviews to

determine if the interview correctly captured what they wanted to say as well as to determine if they wanted to add further information (Merriam & Tisdell, 2016; Moustakas, 1994). Follow up with some participants was made to ask if my preliminary interpretations were true to the experiences they described in the interview (Merriam & Tisdell, 2016)

Data Management

Interviews were recorded for later transcription and analysis. Files were saved by the first initial and last name of each participant. In the event a parent had the same initial and last name (i.e. M. Brown) a number was assigned to the saved file in the order that the parents were interviewed (i.e. M. Brown1 and M. Brown2). Notes were taken during the interview in an effort to recall something that I wanted to follow up on with the parent as they are responding to the question, however, notetaking was limited during the interview to ensure a natural flow of the conversation. After the interview, I created memos to record any reflections, queries, confusions, insights as well as anecdotal observations such as body language, silences, laughs and other exclamations that enhanced the parent's report of their experiences.

To ensure that I had access to the original interviews and was able to contact participants readily in the event of a needed follow up, each audio recording was labeled by the parent's first initial and last name. Transcriptions contained an added section at the top of the interview that included the participants contact information. After each interview, I will review the transcript in anticipation of the next one to determine if or where I should follow up with the parent. This will also assist in identifying where new questions may need to be added based on parent responses (Seidman, 2013).

Human Participants and Ethics Precautions

Ethics

This study posed minimal risks to the participants. The International Review Board (IRB) at the George Washington University ensured that the necessary components and guidelines were adhered to and followed to protect the participants in the study. No identifiable information was released in the study inclusive of the participant's names, school names, or child's name(s). When citing a participant in the findings, pseudonyms were used to protect the participants. All participants were asked to sign a consent to participate form. All forms were locked away in a secured location.

Participant Confidentiality

Because this study involved gathering identifiable information (i.e. participant's name, child's disability, school name if mentioned in the interview), any written transcripts had all identifiable information removed. Only the researcher had access to the key created to decipher changed identifiable information. Original records such as contact information, informed consent forms, and transcribed files were saved under a passcode protected file. Recordings were kept in a safe within the researchers office that was accessible via my fingerprint.

In the event a parent revealed information that I as a mandated reporter was bound to report, the interview would have been ended and the recording of the interview destroyed. In an attempt to be preemptive to such a scenario, it was noted in the informed consent form of my obligation to report cases of abuse as a mandated reporter.

Member checks included having parents review the transcribed interviews to determine if the interview correctly captured what they wanted to say as well as to

determine if they wanted to add further information (Moustakas, 1994).

Summary of Chapter Three

Chapter Three provides an outline for the procedures that were utilized and followed to answer the research questions presented in this study. Basic qualitative design though one-on-one interviews were used to collect data for this study. This chapter provides a framework for the steps and procedures that were followed to gather and analyze the data.

CHAPTER FOUR: FINDINGS

Overview of the Findings

This chapter contains the findings of a phenomenological study of the lived experience of nine parents of children in special education from low socioeconomic (SES) communities and the barriers they face as they make decisions about their child's educational needs. The following chapter outlines the major themes that emerged from the analysis of the parent interviews (approximately 333 pages) and seven pages of researcher-written notes and memos.

In accordance with the hermeneutic phenomenological research approach of the study, this chapter also discusses the analysis conducted and the findings. I engaged in semi-structured interviews with each participant in person when available, or over video link as necessary due to the COVID-19 pandemic. Each interview lasted approximately one to one and a half hours. Analysis of the interviews began inductively as I identified overlapping illuminating phrases from the participants' experiences. This process continued as I identified descriptors and responses that recurred across each interview. Repetitive overlapping phrases that developed into themes began to emerge after the third

interview. As these themes were further developed, they were sometimes added to and sometimes eliminated as interviews continued. By coding against my research questions, I was able to link similar participant experiences together to further refine and interpret themes. Once themes were finalized, transcripts were analyzed again to identify superordinate and subordinate themes. Member checks were conducted with each participant after the transcription was completed. Participants were provided a copy of the transcript and a verbal summary of my interpretation of their experience to ensure the findings I conveyed "rang true" (Merriam, 2009) to the actual lived experience of each participant. Member checks also occurred during the interview through clarifications of experiences during the actual interview.

Research questions that guided the inquiry included the following:

1. How do parents from low SES communities experience their child's disability?

2. What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?

3. How do parents from low SES communities interpret their rights and responsibilities in the educational process?

4. How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?

This chapter also discusses participant demographics, a detailed explanation of the process used to analyze transcripts from each interview to uncover codes, and the themes that emerged from the research.

To protect the identity of the participants, pseudonyms have been used. The participants' experience is written in their own words whenever possible to allow readers to hear the participants' voices most authentically. Some quotes contain an ellipsis (….) to show where words have been omitted to shorten a quote. Occasionally a bracket has been inserted to clarify the participant's words. In an effort to remain true to the lived experience of the participants, the text has been presented verbatim including any lexical or grammatical errors.

Participant Selection

The participants consisted of 9 parents of students with a current IEP that qualified for Free and Reduced Meals (FARM) at their local schools, attending schools in Southern California and Washington, DC. Each participant in the study met the criteria for the participation which included: 1) FARM (free and reduced meals) – children of interviewed parents qualified for free and reduced meals at their school as this was used as a socioeconomic indicator, 2) participants were the parent or guardian and were the educational decision-maker for the child(ren) currently receiving special education services, 3) participants had a child with a current IEP or IFSP, and 4) parents were fluent in the English language.

While parenting can be stressful under the best circumstances, for parents in this study, caring for their child with special needs was a full-time job that was often overwhelming and painful. Eight of the nine participants cried during their interviews when discussing the difficulties they experienced making decisions for their child's special education needs. Although each tried to remain stoic in their facial appearance

and verbal responses, they were unable to hold back tears as they described their experiences.

The names of the participants and their children have been changed due to confidentiality. Demographic information on each participant is listed in Table 7.

Recruitment, Confidentiality and Member Checking

As outlined in Chapter 3, participants were recruited through flyers, snowball sampling, and referrals. Flyers (Appendix B) were distributed to school officials and teachers as well as to community-based organizations that serve families and/or children. Participants were asked to refer other parents to participate in the study. Prior to their participation, participants were given a consent form describing the purpose of the study, potential benefits and risks (Appendix A). Interviews were recorded on a voice recorder for transcription. Transcribed files were saved as password protected files. Interviews were transcribed by the interviewer and by a transcription service, Rev. Accuracy of the interviews was confirmed by this researcher. Data were coded and analyzed using Dedoose software. Themes that emerged from the clusters of coded data imparting connections to the research questions were identified.

Participant data was protected through the removal of all identifiable information such as personal and school names, and changing non-essential details to the research. All data was saved under password protected files. Printed documents were saved in a finger print accessible safe.

For their participation, participants were offered a $10.00 gift card to a local grocery store. Grocery cards were delivered with a copy of the transcripts of the

Table 7

Study Participants Demographic Information

Participant	Yearly Salary range	Occupation	# of Children with IEP	Single Parent	Child (ren) Disability	Total # of people supported on salary	Race	Highest Level of Education	Location
Ms. Red	$0 – $20,000	Program Assistant	1	yes	Down Syndrome	3	Hispanic	technical (obtained out of the USA)	DC
Ms. Green	$0 – $20,000	Unemployed/ caregiver	1	yes	OHI (ADHD)	3	Laotian	10th Grade	Southern CA
Ms. Orange	$0 – $20,000	Secretary	2	yes	Autism/ Speech & Language Impairment	4	Hispanic	some college	Southern CA
Ms. Blue	$0 – $20,000	Receptionist	3	yes	Intellectual Disability/ Learning Disability *(2 children)*	4	African American	some college	DC
Ms. Sienna	$21,000 – $30,000	School Assistant/ Secretary	1	yes	OHI (ADHD)	3	Hispanic	some college	Southern CA
Ms. Cerulean	$21,000 – $30,000	Transportation	1	yes	Autism	2	African American	some college	Southern CA
Mr. Purple	$21,000 – $30,000	Waiter/ Overnight Stocker	2	yes	ED/ MD & MD	3	African American	High school	DC
Ms. Pink	$41,000 – $50,000	Security	2	yes	Deaf and Hard of Hearing *(both children)*	3	African American	associate degree	DC
Ms. Yellow	$50,000- $60,000	Secretary	1	yes	Autism	5	Hispanic	some college	Southern CA

interview to the participants either in person or via mail. For mailed items, addresses were written onto an envelope for delivery only and not kept by this researcher. Member checking was conducted twice. First, immediately after each interview, participants were asked if there was anything they did not want shared in the final study. Second, each participant received a copy of the transcript to review (Seidman, 2013).

Participants were asked if there were any parts of the transcript with which they disagreed. Participants were asked if they were comfortable with the inclusion of certain details, with the understanding that their identity would be obscured to the greatest extent possible (i.e., name changes).

Participant Profiles

Below is a detailed description of each participant. Descriptions are included to assist readers with understanding the parents' lived experiences of raising a child with a disability. To understand each participant's experience, it is important to understand their backstory. Names and other information that would make the participant identifiable have been changed to protect the participants' confidentiality.

Ms. Orange

Ms. Orange is a single parent of Hispanic descent living in Southern California with her mother who helps her to care for her children. Ms. Orange has two children receiving special education services. Ms. Orange has completed some college but currently works part time in finance. Two of her children have been diagnosed with a disability. Child #1 is diagnosed with high functioning Autism and Child #2 is diagnosed with a Speech and Language Impairment. Child #2 is currently not receiving services because the family is in the process of moving, and Ms. Orange does not want to start her in a school while they are in the process of moving.

Over the past five years she has moved five times, each time to a different state. She is currently looking for a new place to live because the condo she is renting has been sold by the landlord. He has given her 60 days to move. She is unsure how she is to find a new place while still paying rent at her current place. In addition to the many moves over

the past five years, Ms. Orange has experienced multiple traumatic experiences. She lost her dad to cancer on her child's birthday, divorced her husband while pregnant, was in an abusive relationship after her marriage (her ex is now incarcerated due to his domestic violence towards her), and lost her cousin to murder. This past summer her employment status changed from full time to part time, unrelated to the pandemic.

Ms. Orange had Child #2 when Child #1 was 18 months old. Ms. Orange notes the fathers of the children were not present for either pregnancy. She wishes schools would provide more support in the home. She also wishes they would organize everything they send home into a binder, like they did in a different state for her. She feels this makes it easier to find the information she is looking for, rather than the school putting a bunch of loose papers into her children's bookbag.

Ms. Orange is currently struggling with the school calling her to pick up Child #1 when she refuses to get on the school bus after school. When she refuses to get on the bus, staff take her to the office and call Ms. Orange. This requires Ms. Orange to leave work multiple times a week, make a minimum of a 45-minute drive to the school, drop Child #1 off at home, then drive 45 minutes back to work. She notes that her boss is very flexible and understanding but worries how long she can continue to keep up such a pace. When she went to complain to the teacher, the teacher gave her my flyer and told her to contact me. Ms. Orange works part time as a secretary. It is unknown how the pandemic affected her.

Ms. Yellow

Ms. Yellow is a single parent of Hispanic descent with multiple children. She resides in Southern California. Ms. Yellow works as a secretary and is currently enrolled

in college. Her highest level of education is some college. At the time of the interview, one of her children was diagnosed with Autism and a genetic syndrome. The genetic syndrome is a developmental disorder whereby the signs and symptoms vary amongst those affected. Common symptoms include poor muscle tone, intellectual disability, ranging from mild to profound, although it is usually in the moderate to severe range (National Institute of Health, 2020). Speech and Language are impacted with some individuals never developing functional speech. Most individuals identified with this disorder are also identified as having autism spectrum disorder (ASD). Behavioral problems associated with the genetic disorder include those similar to ASD such as difficulty with social interactions and changing routines. (National Institute of Health, 2020).

The non-resident father of Ms. Yellow's child with a disability is involved, but does not agree that their child has a disability. He acknowledges the child is "different" but feels the issue is that he needs more discipline. This is a source of contention between the two parents as Ms. Yellow is willing to spend whatever money she can to support her child, but Ms. Yellow reports that the father is less willing to use financial resources to support him. The child has received special education services since he was three, because at age three he was nonverbal.

The child is an average height male with severe delays in speech and cognitive ability. He struggles with basic phonemic awareness, reading comprehension, fine motor skills which impact his handwriting, transitions and social interactions. He can be overly affectionate to strangers and staunch in his task refusal to a non-preferred task. When presented with a non-preferred task, he will abscond. He was in a full-time special

education class until first grade and then switched to a general education class. Ms. Yellow is adamant about her son staying in a general education class as he tends to mimic what he sees other children doing. Ms. Yellow wants him to imitate the behaviors of his non-disabled peers.

Ms. Yellow's greatest fear is that if something happens to her, there will be no one to care for her son as her family members do not include him in activities because they find him "too difficult". Simple trips to the movies are hard as her son can become overstimulated by the sounds of the theater and requires frequent breaks to step out of the movie. If overwhelmed he will begin to scream, which frustrates family members.

Ms. Yellow works as a secretary. Her hours were reduced due to the pandemic and she had to alternate to a modified schedule of working in the office two days a week. During the Covid-19 pandemic she had to find childcare for the days she was at work as the children were all out of school.

Ms. Cerulean

Ms. Cerulean is a single parent of African-American descent with one daughter. She lives in Southern California. Her highest level of education is some college. Her daughter is in the 12th grade, was diagnosed with ADHD in the 5th grade and recently, during her senior year of high school and was diagnosed with Autism. Due to the parent's concerns about her "odd behaviors" (difficulty making friends, following social hygiene norms of bathing and cutting hair regularly, difficulty with transitions and fixation on certain topics) she asked that she be reevaluated at the school. Her daughter was also experiencing emotional breakdowns at her job when things did not go her way. She would scream and fall out on the floor and become very agitated when things did not

make sense to her. Academically, her daughter is on the honor roll. Ms. Cerulean initially stated that her daughter had an IEP, but after reviewing her documents, we determined that she had a 504 plan. Her daughter did not receive an IEP until the Autism diagnosis her senior year. Ms. Cerulean is extremely upset because she feels that she has spent years addressing the wrong disability, and her daughter graduates from high school this year. She is scared that her daughter is not ready to go into the adult world. She plans for her to attend community college, but worries about her ability to become independent. Her daughter's father is not involved in her life.

Ms. Cerulean's demeanor changed dramatically when the tape recorder was on. She presented as extremely guarded during the interview both physically and verbally. Her body tightened and her speaking became choppy and cautious. At one point in the interview she asked that the recorder be turned off as not to capture what she was describing. She is currently going through a family battle that includes non-resident family members calling the police on her. Although no charges were made in this incident, Ms. Cerulean is guarded about what she says. Ms. Cerulean works in transportation. She was laid off due to the pandemic.

Ms. Sienna

Ms. Sienna is a single parent of Hispanic descent with multiple children. She has one child (Child #1) that receives special education services. Ms. Sienna lives in Southern California. Her highest level of education is some college; however, she is currently in college working towards a degree. Child #1 receives services as a student with an Other Health Impairment due to an ADHD diagnosis. Child #1 has received services since the first grade. Child #1 began taking medication for ADHD near the end

of their first grade year. Ms. Sienna reported she was initially reluctant to give Child #1 medication because she thought of medication as a narcotic and did not want Child #1 to be under the influence of narcotics. However, she reported that over time she began to change her mind because she was having a difficult time with Child #1 at home. Ms. Sienna also reports a self-diagnosis of anxiety that affects her daily activities. During the interview, Ms. Sienna spoke quickly and often seemed to interpret situations in her daily life from a negative perspective. She noted that her anxiety overwhelms her in day to day decisions and causes her to "shut down" making it difficult for her to speak up for herself. When speaking up for her children she described herself as turning into the "Hulk" and reported that this stance can cause others to see her as having an attitude, but when needing to speak up for herself, she keeps it in and just tries to move on. She described her near constant battle against an internal dialogue that she is a "bad mother". Throughout the interview, she often stated that she thought others thought she was a bad mother. When questioned why she believed this to be the case, she was unable to articulate why, but did note that the school counselor mentioned to her that she thought she was a bad parent. Her husband and father of the children is serving 11 years in prison for domestic abuse against her. He calls regularly to speak to the children. Child #1 only knows the father through their phone conversations as he was arrested shortly after Child #1's birth. Ms. Sienna faults herself for her child's ADHD due to the beatings that occurred while she was pregnant. She is fearful of what will happen once her husband is released from jail and does not want him to know where they reside, but does not know how to allow him to keep contact with the children yet away from her. Through her college course work Ms. Sienna is learning that she is not to blame for her child's

diagnosis and is learning the role that trauma plays on a developing fetus. Due to the pandemic, she has lost her job as an aide and works part time as a secretary.

Ms. Blue

Ms. Blue is a single mother of multiple children of African-American descent. She lives in Washington, DC. Her highest level of education is some college. Three of her children receive special education services. Two have been diagnosed with learning disabilities and the other, an intellectual disability. Ms. Blue is reluctant to identify her child as having an Intellectual Disability due to how others will perceive her. She thinks that others will perceive her child as less competent and thus expect less of her. She also feels that she was mis-identified because the psychologist that conducted her testing was a "foreigner" and thus unable to bond with her during the assessment. Because of this, Ms. Blue tells people that her daughter has a learning disability, despite her being a teenager and unable to ride a bus by herself. Ms. Blue also accepts that her daughter will never be able to live on her own. When asked if the school had conducted new testing that changed her daughter's disability from an Intellectual Disability, she replied that she just "learns differently like everybody else." All of her children were premature births arriving at 23.5 weeks, 24 weeks and 25.5 weeks. The child identified with an intellectual disability has the most delays of the siblings. Ms. Blue noted that none of her children were expected to live past the age of 5 due to their delays.

Her history with the children includes a "bad" marriage that resulted in divorce and homelessness while going through the divorce. She describes the marriage as bad, but also notes that she is unable to remember everything good or bad that happened because remembering them "triggers" certain things for her. Although the children all

have the same father, he is not active in their lives. Over the past three years she has obtained a job and secured stable housing for she and the children. Ms. Blue works as a receptionist. Her hours have been cut due to the pandemic.

Ms. Red

Ms. Red is a single mother of Mexican descent. She has one child, who has been diagnosed with Down Syndrome. She lives in Washington, DC. Her highest level of education is a technical degree she earned in Mexico. She needed two more years to become an engineer in Mexico. She was going to begin the process of transferring her credits over to continue her studies here in the U.S. where she wants to study Special Education and Administration. She has not continued her studies due to her husband's passing and the birth of her child. She is uncertain of her degree's equivalent here in the United States. Ms. Red lives with her mother as an additional support system for the family. Ms. Red disagrees strongly with the word "disability" to describe her child. She has no problem with the diagnosis of Down Syndrome but becomes upset when you say it is a disability because this implies that her child cannot do something. Her daughter is the third person in her immediate family to be diagnosed with Down Syndrome. Ms. Red's experiences of growing up around other family members who have Down Syndrome shapes her view of what a person with Down Syndrome can do. She notes that many of her family members assume that they, as well as her daughter, will not be able to have productive lives, yet she has watched other family members with Down Syndrome become bilingual and live productive lives on their farm in Mexico. Ms. Red often finds herself on guard around her family members because they will refer to her daughter as a mongol, because her face looks like someone from Mongolia. For her culture, this term is

the equivalent version of "retarded." Although people do not mean it disrespectfully and use the word in phrases such as "ay que probrecita, que bonita la mongolita" (oh poor little cute Mongol), she finds it extremely disrespectful to refer to her daughter this way. She wants everyone to see her child as "her daughter, period" and "her daughter the ….." but not as her daughter the mongol or her daughter the disabled.

She advocates that her daughter remains in a general education classroom and is adamant that she not be placed into a specialized school because she wants her to be around other non-disabled children. Currently the school is looking to place her into a full day special education class where all of the students have an IEP. She is agreeable to this idea as she will still be in the neighborhood school participating in lunch, recess and special subjects with her non-disabled peers. Her daughter is the only child with Down Syndrome in her school. She has two teachers, one for math and one for ELA. Ms. Red does not get along with the math teacher because she feels that her daughter should be with other children with Down Syndrome. Ms. Red really likes the ELA teacher because she always pushes her daughter and although she thinks a special education class would support her daughter, the teacher discusses it based on the child's skills and not the child's disability. What Ms. Red did not seem to know is that the ELA teacher is a dually certified Special Education and General Education teacher whose background includes teaching a transition program that contained half of the students having an IEP and the other half without. This researcher knows this because of her previous work experience with that teacher.

Of all the parents, she is the only one that spoke of systemic change, beginning with the terminology we use to describe students with disabilities, specifically to stop

saying disability. She also wants to change how disabilities are presented in the public. When discussing disabilities and a picture is included, it is either someone in a wheelchair or someone with Down Syndrome. Ms. Red would prefer to see such images as a part of our day to day activities and not only when discussing disabilities. She is actively involved in an education community rights organization called PAVE (Parents Amplifying Voices in Education).

Ms. Red works as a program assistant in a school. She lost her job during the pandemic.

Ms. Pink

Ms. Pink is single mother of two children of African American descent. She lives in Washington, DC. Her highest level of education is an Associate's degree, but she is currently in school studying to obtain a Bachelor's degree. She currently works in security. Both of her children have a moderate to severe hearing loss that is not due to a genetic disorder. The doctors are unable to determine why both of her children have a hearing loss. Both children have a cochlear implant. For both children, their speech is severely impacted by their hearing loss. Both children struggle to pay attention in large class settings due to difficulties hearing. Child #1 has been placed in a program for the Deaf and Hard of Hearing where all of her classroom peers have a hearing impairment. Ms. Pink worries that her children are being pushed through school because they are in special education. She has argued to place her children in the schools they are in (both public) because she feels that the teachers there are more concerned about them. She also thinks the children were not pushed as hard at their previous school due to them being one of the few African American children in predominantly white schools. Although

Child #1's current teacher is white she describes her as "cool" because she makes the effort to break information down for Child #1 and "acts like one of us".

When describing the children's disability, she is able to describe it in minute detail, unfolding how their hearing loss impacts their ability to hear different sounds spoken at different frequencies. This impacts the children's speech because they may not hear certain sounds in a word that are produced at high versus low frequencies.

Ms. Pink works in security. Her hours were reduced to part time during the pandemic.

Mr. Purple

Mr. Purple is a single father of two, one boy (11) and one girl (13), of African-American descent. He lives in Washington, DC. His highest level of education is high school. The family is currently homeless. He describes himself as a wartime veteran. He has ADHD.

Interviewing Mr. Purple was difficult due to his rapid talk and frequent tangential off topic comments when talking. It was difficult to bring him back to the question at hand, as he would begin to respond then jump to a story within his response that then led to another story. He carries a bag full of papers and pamphlets. He notes that whenever he sees a pamphlet, he picks it up because you never know when the information will be useful. One of the papers was the IEP for his son.

He is currently in the process of suing for sole custody of the children from the mother because she does not send the children to school when she has them. He has filed a child protective services case against the mother for failing to take the children to school. They have been to court six times to determine who has decision-making rights

for the children. Currently the mother has educational decision-making rights, but Mr. Purple is the only one who interacts with the school as the school notes they have never seen the mother. He states that at the last court ruling he was awarded educational decision-making but the official paperwork had not been filed yet. When the parents were together, he saw his role to be the financial provider and the mother to be the disciplinarian. Now that he is a single parent, he struggles to balance both roles and feels the children try to "get over on him," especially his son. At some point, Mr. Purple's father, the grandfather, was making decisions for the children (ADHD medication, getting glasses) but it is unclear to what extent the grandfather was involved.

Both children have cerebral palsy. His daughter has a shunt in the back of her head to assist with drainage that runs to her bladder due to hydrocephalus. She used to have seizures, but has not had one in a few years. He describes her disability as a developmental delay although she is thirteen years old. When describing the son's disability, he describes it as behavioral and gives a complex description of having to physically flip his stomach as a toddler to allow him to eat. Based on the IEP he had in his bag, the son's diagnosis is Multiple Disabilities, Emotional Disturbance and Other Heath Impairment. He is in a full-time program for students with Emotional Disturbances. Mr. Purple thinks his son had ADHD but cannot recall if the doctor has provided an official diagnosis of ADHD. He is more concerned that he does not want his son on medication because he himself does not take medication and has "turned out fine." He is also against medication because his son is "nice" and believes that is all his son needs to get through life. Mr. Purple explains that the son's emotional disturbance is partially due to the separation of the parents and that the mother has "brainwashed" him

by making disparaging remarks about him as a parent. He worries about the daughter's ability to be independent because he spoils her. He is not worried about his son's future because of his strong social skills. Even if he falls behind academically, he feels that his son will be fine. Mr. Purple works as waiter and an overnight stocker. He lost his waiter job during the pandemic.

Ms. Green

Ms. Green is a single mother of one boy with a disability, Child #1. She is of Laotian descent. Her mother also lives with her to provide additional support in the home, but Ms. Green has to help care for her too as she is 76 years old. Ms. Green and her mother speak Laotian to one another, but Child #1 prefers to speak in English. Ms. Green's highest level of education is tenth grade. Her son qualifies for special education services as a child with OHI due to his ADHD diagnosis. He was first identified for services after repeating kindergarten in SY 2016-2017. Earlier that same year, Child #1's father was killed in an accident. Child #1 receives counseling for the loss of his father and continues to receive counseling services to date to address behavior concerns. Ms. Green does not and has not received counseling services. Although she and the father were no longer together at the time of his death, they had a healthy co-parenting relationship.

Ms. Green's greatest fear is that she has failed her son and he will turn out like her by not completing high school. The school closures have been difficult for her as she has struggled to help her son with some of his assignments because he does not know how to do the work himself. Although he watches the tutorials given by the teacher, he does not always catch onto the concept.

Ms. Green has not been to an IEP meeting since her son was identified for special education services due to her work schedule. She works as a caregiver from 2-10 each day. She gives the school permission to go forward with the meetings in her absence. After the meetings, the IEP is sent home for her signature, but no one contacts her to talk about what was changed. She does not have a rapport with the special education teacher and has had very few conversations with her. The only teacher she talks to with a modicum of frequency is the general education teacher. However, this may be limited as the grandmother drops off and picks up Child #1 from school due to Ms. Green's work schedule.

Interviewing Ms. Green required observant attention to her body language as her verbal responses did not match her physical affect. An example of this included when she was asked if she thought her son was receiving the education he needed to be successful. Ms. Green replied "yes" but was tearing up. When asked about what caused the tears, she noted that she was afraid that she was failing her son because she cannot always help him when he needs help with his school work. She thinks her son needs more help and is not remembering everything taught in school. After many rounds of responses that did not match her physical response, and this interviewer asking about her physical response, Ms. Green's responses began to match her external affect. Overall, Ms. Green was particularly non-confrontational and reluctant to say something that could be perceived as deleterious about another individual. This was not done cunningly, but more as a politeness, or civility, as though speaking ill of another would be bad-mannered.

Ms. Green works as a care giver, but lost her job during the pandemic. She is currently unemployed.

Participants Summary

Despite the similarities in their demographics of being parents from low SES communities with a child receiving special education, their profiles illuminate the differences of each family's actual reality. Just because the participants in this study are each classified as "low socioeconomic", "parent" or "has a child with a disability" does not mean their experiences or skill sets to navigate special education day-to-day are uniform. The strength in conducting a phenomenological research study is that participants can have uniquely diverse sociocultural experiences while still revealing the commonalities among their experiences.

Data Collection

After recruiting the participants and securing informed consent, semi-structured one-on-one interviews were conducted with each participant. The audio recorded interviews were transcribed, analyzed and reviewed as described in Chapter 3 to reduce, label and sort the data. After each interview, meaningful passages were identified (reducing data). In a second reading of the interview, meaningful passages were labeled and placed into categories based on the research question they answered (labeling). Once four interviews were completed, a third review of the interview passages was conducted to initiate identifying emerging themes (classifying) (Saldana, 2016; Siedman, 2013).

Interview questions (see Appendix C) included a mixture of open-ended and topic-specific questions to gather information around the following themes: knowledge of child's disability; procedural safeguards manuals; knowledge level of special education law; how/where the parents seek out answers when uncertain about something pertaining to their child's IEP; and recommended areas for improvement.

Data and Analysis

Qualitative research methodologies collect open ended data that can be used to develop themes (Creswell, 2003). Such methods are useful when research seeks to understand experiences. Research that focuses on the lived experiences of individuals is the foundation of phenomenological research. This study focused on the lived experience of parents from low SES communities as they make educational decisions for their children with special needs. Because this study was conducted to find common themes among a population's experiences, phenomenology was the most appropriate qualitative methodology.

Phenomenological inquiries are utilized to further develop the qualitative frame of a study. This methodology assisted discovery and understanding within the data rich environment evolving from the lived experiences of the parent participants. Where some methodologies strive to determine the opinions and a generalization through hypotheses, a phenomenological approach seeks to explore contextual meaning through the situational knowledge of those being researched (Creswell, 2009).

Methods common to phenomenological research guided my data collection and analysis. The results were a culmination of the parent's voices and revealed a deep perspective into their lived experiences. This study utilized a transcendental phenomenological approach (Moustakas, 1994) to assist in understanding the lived experiences of parents from low SES communities when making decisions about their children's educational needs. Similar to phenomenological research, transcendental phenomenology, is used to describe "what all participants have in common as they experience a phenomenon" (Creswell, Hanson, Plano & Morales, 2007, p.252). To study

how parents experience and understand their decision making while navigating the special education process, I created my research framework based on the following questions:

- RQ1) How do parents from low SES communities experience their child's disability?
- RQ2) What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school
- RQ3) How do parents from low SES communities interpret their rights and responsibilities in the educational process?
- RQ4) How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs.

Semi-structured interviews were conducted in private settings in person or via Zoom. All interviews were scheduled ahead of time by the researcher. The interview protocol (Appendix C) was used as a guide throughout the interview process to ensure consistency across interviews. Interviews were recorded using a voice recorder. Additional notes were made afterwards to document body language, facial expressions and other observations not captured by the recorder. All interviews were coded manually initially. Reduction of the interview data occurred prior to the completion of the next interview to allow analysis time prior to the next interview. By reducing the data between interviews, the researcher was able to identify if/where further questioning was needed and where

rephrasing a query was necessary to gain significant insight. This process also allowed the researcher time to reflect on behavioral likenesses shared between participants.

After the initial manual data reduction, transcripts were uploaded into the qualitative analytical software, Dedoose for further analysis. Using Dedoose, meaningful passages were placed into categories based on the research questions. This process helped the researcher remain consistent in emphasizing key points during the coding process and focusing on how responses connected to the research questions. The labeling process resulted in the application of 68 codes in Dedoose.

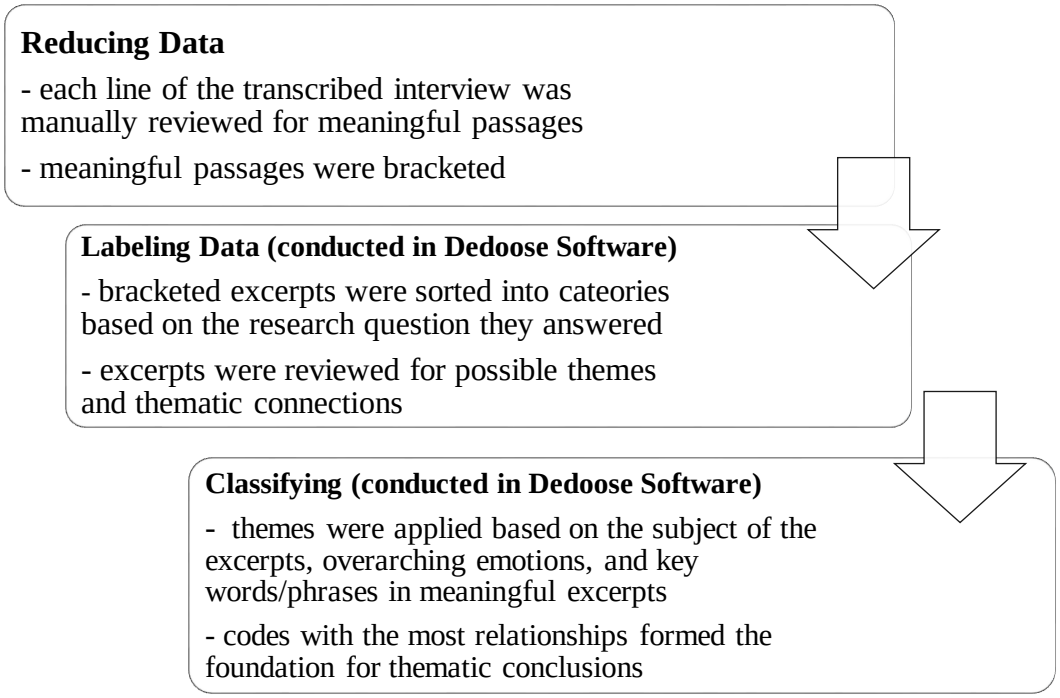
In the final phase of analysis, classifying, the process of labeling and sorting the data, the researcher concluded with identifying thematic connections between the responses in a given category. Figure 6 includes a summary of the data and the analysis process for reducing, labeling and classifying the data.

All questions from the interview protocol were asked. Due to the timeline of when interviews were held, not every participant had an initial opportunity to speak about the COVID-19 pandemic as some were interviewed prior to the pandemic. Once a theme began to present itself for parents interviewed during the pandemic, a follow up phone call was made to those parents interviewed prior to the pandemic to determine how/if they were impacted by the nationwide shutdown. Parental responses revealed multiple themes.

Based on the analysis of parental response data, 10 superordinate themes emerged: (1) experiencing my child's disability, (2) navigating the landmine of special education, (3) communication, (4) trust, (5) trepidation, (6) isolation/self-reliance, (7) finding resources: why is it so hard?, (8) I don't know my rights, (9) extenuating

Figure 6

Data and Analysis Process for Reducing, Labeling and Classifying Data.



circumstances, and (10) COVID-19 pandemic. Table 8 provides a visually organized overview of the superordinate and subordinate themes that illuminate the lived experiences as shared through the participant's interviews which will be discussed in this chapter.

Table 8

Superordinate and Subordinate Themes Established From Interviews

Superordinate Themes	Subordinate Themes
Experiencing my child's disability	a. Medical versus non-medical disabilities b. Assumptions about me/my child c. I just worry about their future d. Passing students along
Navigating the landmine of Special Education	a. Creating relationships b. I make myself heard c. Balancing my parenting responsibilities when at work
Isolation/Self-Reliance	a. I put myself on the back burner

Extenuating Circumstances	a. You don't know my full story
Communication	a. How you talk to me matters: Use a Method that Works for Me b. How you communicate with me determines our working relationship
Trust	a. Our communication influences my trust in you b. Trust and race relations
Trepidation	a. If I don't, no one else will fight for my child
Finding Resources: Why is it so hard?	a. It's like a hidden secret b. Too many resources to organize
I don't know my rights	a. Interacting with the Parents Rights and Procedures Manual b. Improving the Manual
Covid-19 Pandemic	a. Loss of income b. Distance learning

Theme: Experiencing My Child's Disability

Medical Versus Non-Medical Disabilities

To determine how parents of children with disabilities experienced their decision-making processes around the education of their children, it was critical to understand what they understood about their child's disability. Parents fell into two categories when describing their child's disability, 1) understanding the nuances of the disability to explain it in practical detail to another person, or 2) having a surface level understanding of the disability, where they may or may not have known the disability name under IDEA, but might be able to identify the diagnosis (i.e., ADHD) as the disability and describe some parts of how the disability impacted their child. (i.e., it keeps the child unfocused).

Parents that were able to describe their child's disability in explicit detail all included those with medical components such as Deaf and Hard of Hearing or genetic components to the disability. These parents were also able to describe how their child's

disability impacted their learning. When describing how her children's hearing impairments impact their ability to interact, Ms. Pink noted

> *"<She> has a worse hearing loss than <her brother>. Both [have hearing loss] in the high frequency, but hers dropped off significantly. <her brother's>, it stays stagnant and then it drops off. It declines. Speech is a big deal. If we are sitting down to talk to <my daughter>, or even <her brother>, you have to make sure you look them in their face at their eye level so they can understand what you're saying. Most of the time, I know with <her brother> he's reading my lips most of the time. If I'm talking to him from behind, he will miss stuff. That's why I always make sure, "Stop, turn around, look at me." Hopefully there's no background noise, which there always is. I have to repeat myself most of the time."*

She went on to describe the difference between the children's reliance on their hearing aids versus their cochlear implants when trying to decipher sounds.

> "*My daughter's <hearing> drops off <without the hearing aid>. On the chart, it stalls out and then it drops down. With the hearing aid, it brings her up to a whisper, but she still doesn't hear the high frequency. The Cochlear implant helps with high frequency.....The high frequency, she never heard those sounds before so they're foreign to her. I'm not sure if her brain knows how to identify what she's hearing. She don't know what to do with the information. <High Frequency sounds> are like the c-h's, s-h's."*

Ms. Red's daughter is diagnosed with Down Syndrome. When asked to describe Down Syndrome she reported,

> *"<My child> has trisomy 21 by the translocation. She is the 4% of 100% percent, 95% of the kids has an extra chromosome, but that 4% kids with Down's Syndrome have, it's only by translocation and only 1% pass the translocation, fully translocation. That means <my daughter> doesn't have an extra chromosome. The chromosome on the 14 moves only to the 21 so the other rest, one chromosome is correct, so <my daughter> is a very rare case. The doctor checked my chromosomes, my husband's chromosomes and they determined that there's more in <my daughter's>. It's like the chromosomes are playing with your daughter."*

Ms. Red is currently advocating that her daughter remain in the general education setting while the school is advocating a full day special education class. Ms. Red is against this as she feels her daughter has not only the ability to learn from her typical

developing peers socially but is also too young to be separated from them at this point. She makes her argument through stories about her daughter's ability to understand abstract concepts and use the information to respond appropriately. Ms. Red is not in denial that her daughter may have delays due to her Down Syndrome diagnosis, but she does not believe the expectations of her daughter should be limited based on those delays. Some of the experiences she shared to support her thoughts included the following:

> *"She may have some delays from those <genetic anomalies >. She has checkups with genetics every year. The last year, the last checkup, was some months ago and <the doctor> said that she is developing like a six years old kid and she knows more than she can express because of her talking abilities. She still needs speaking therapy. She knows everything. She can speak Spanish and English."…… "Right now we are counting up to 100. She knows the letters in Spanish and English, the sounds. We are working in addition and also the reductions <subtraction>. It's not like she doesn't know. She knows. We know that she knows more than she can express. She learns very fast and has memory."*

To demonstrate her daughter's ability to grasp and apply what she sees Ms. Red shared two stories about her child. In the first story she shared,

> *"She's paying attention on everything. Yesterday she told me that I had two eyes and ears and two boobies. I was like, "Yes." She was like, "Can I touch?" and I was like, "Okay, go ahead, touch it." And she was like, "Oh wow, boobies are for babies." I was like, "I don't have babies around," but I have two cousins with little babies and they were breastfeeding the babies and probably she saw this."*

In her second story Ms. Red shared,

> *"So when I showed her the hospital, I told <my daughter>, "You know, Daddy's going to heaven. He's going to be with us, here, and this and that." So when he was declared dead, I walked out from the room and I just was looking for <my daughter>. And I gave her a big hug and I was crying. And she just put her face in my chest and she let me cry. She didn't do anything. She just was like here <pointing to her chest>. And when I was like calm, she grabbed my face and she smiled. And I was like, do you know what? Everything is going to be fine. And when we came back, she never asked for her dad anymore."*

Where Ms. Red and Ms. Pink were able to describe their child and disability, Ms. Green's son who has a diagnosis of Other Health Impairment, when asked about what her

son's disability is and how it impacts his learning, reported that her son's disability is *"reading, writing and math".* She struggled to name the type of disability. When asked how the disability impacts her son's learning she responded:

> *"He's very distracted. I guess he has, what is it? ADHD or something, and I was trying to get some help with that, but I'm not sure if I want to put him on medication because I hear bad things, and I also hear good things, so I'm working on that right now with the counselor, I've been in counseling with him since he was like five years old, four or five. Yeah, four years old."*

When asked to describe her daughter's disability, Ms. Orange replied the following,

> *"<My daughter> has autism, she was diagnosed when she was two and a half, actually in the state of Montana. She is high-functioning. She has her meltdowns just like any kid would but it's a little bit more intensified for her. She gets overstimulated sometimes. She cries a lot when she is tired and she'll have a hard time going to bed at night. But she will not want to wake up in the morning like a normal person. But when she was younger, she would cry all the time and I didn't realize it. ….Mostly, she's manipulative. Even though she's a great kid, she knows what she's doing. That's why I'm saying the intelligence is there. It's not an intelligence issue, autism is a different way of thinking and there's so many different levels of it. That they only gave her the level basically for services because she can articulate a lot. She can express something's wrong with her, she can make eye contact, she can smile. She actually talks a lot."*

Based on the parent's responses, their knowledge of their child's disability impacts their ability to advocate successfully for their child's needs. Parents that understood their child's disability at a level where they could describe how the disability affected their child were able to describe what their child needed to be successful learners. Such nuances of learning are key components to share with not only teachers of their children to ensure mastery of academic skills, but also in understanding how a parent makes requests for additional support in their child's learning regardless of what they know about special education law.

Assumptions About Me/My Child

The parents in this study described multiple strong assumptions shared with them in their experience of raising a child with a disability. These assumptions fell into two categories 1) assumptions about the parent of the child with a disability, and 2) assumptions about their child due to their disability.

Whether through interactions with school staff or family members, judgements about the parent's behavior, intentions or personal affect resulted in adverse reactions from the parents. Four parents summarized this sentiment in their interview.

When discussing why her child had not completed some assignments during the Covid-19 school closure, Ms. Sienna reported the following feelings after talking with the general education teacher.

> *"I felt like kind of threatened and I felt like he <the teacher> thought that I was a bad mom and I'm like, dude, I'm working two jobs. And I was just like, "You have no idea what the hell I go through. How can you judge me when you have no idea what I've been through or what I am going through?"*

For both Ms. Blue and Ms. Red, assumptions were made about their ages based on their child's disability. Ms. Red, after sharing her story of being assigned a translator when she said she did not need one, shared a frequent assumption made about her based on her child having Down Syndrome. Oftentimes she noted that people assumed she was older. In this instance she described her conversation with the translator.

> *" I thought you we're older. And I was like ... older? No honey, the biggest percentage of mothers with sons and daughters with down syndrome are younger. It's just surprising when they have assumptions about me, because it's like they need to read a little bit more!"*

Ms. Blue shared an incident with a provider when she was having one of her children assessed.

> *"And I also think that he looked at me - maybe because of the fact that I look younger than what I am. And I'm sure back then, I was probably what, in my...*

Well I was in my thirties, because I was over 30 by the time I had them. Yeah, I was already in my thirties. And he's probably looking at me that I'm this really young mother who's... probably a drug addict, and this and that, and making assumptions that probably weren't accurate. I was a mother of four at that time, who was in a marriage that was unbearable, but I had to do what I had to do. But I think he just looked at appearances and things like that, instead of really doing a really good assessment.

Assumptions Others Make About Their Child with a Disability

While some parents described incidents assumed about them as a parent of a child with a disability, other descriptions included assumptions about their children that elicited feelings from the parents that others did not need to expect much from the children because of their disabilities. Two parent's description of assumptions made about their child adequately details what other parents described.

Ms. Red describes the pain of fighting assumptions made about her daughter before she was born.

"*When I was pregnant and doctors pushed me to terminate my pregnancy, it was like, "Because your daughter is going to be a disability." And I was like, "What do you mean about that?" He's like, "She may not be able to walk, to do a job, even call you mom." I think that label is something that doctors assumed because my daughter is way more than that. It's an assumption. It's something that you assume already. They assumed that my baby has disabilities even though she hadn't been born and even though they haven't given her the opportunity to prove and show that she's able to do that. … I agree, if they say, "Oh, she is disabled after they gave this person the opportunity to do some tasks and the person wasn't able to do that ...but they hadn't seen her."*

Ms. Yellow describes the experience of people mocking her son once they realize he has a disability.

"If you look more like a typical child, people treat you better. Those people make fun of you because there's a lot of ignorance in the world. And I've had people make fun of him even as ... people can tell that there's something off <with my son>, but it's not real visible or it doesn't strike you right away. I just want him to have the least amount of trouble or difficulty as he grows up. If he behaves more as a typical child, I feel he'll be better off."

When describing these experiences, each participants' voice level increased to an agitated tone, hands were used in gesturing/pointing/slicing manners to emphasize points and shoulders tightened about their necks.

Additional pressures are mounted on parents when assumptions are made about their race, age, and/or marital status. In context with the quotes from the parents these assumptions imply to the parent that their personal circumstances had something to do with the manifestation of their child's disability.

I Just Worry About Their Future

The third subordinate theme to emerge in how parents in this study experienced their child's disability was their concern for their child's future. When discussing their child's future, eight out of nine parents mentioned words such as "worry", "scary", "afraid" or shook their heads in the negative while looking down. Although parents tried to remain positive and would quickly revert to where their child had strengths, or initially shared how their child would be fine, as rapport between the parent and I increased, this question was readdressed later in the interview, and answers changed and tears flowed. Body language changed to parents grasping their heads or holding their hands over their hearts. The initial question, early in the interview, asked parents how they felt about their child's academic future, where parents often answered in the positive. When parents mentioned that they thought their child was being pushed through school, or commented on experiences they had with a school, the question was rephrased to "Do you think (student) is learning what they need to be successful, or "Do you think (student) is learning what they need to be a successful adult?" Once re-promoted, the following responses were given.

Ms. Orange's fears were a summation of not knowing if her child was receiving all of the education she needed to be successful. She shared:

> *"Right now, I'm not sure… I don't really know if she's getting all the education she's needing. I feel sometimes it is what it is."*

While reflecting on her child's future, Ms. Yellow shared her fears about her son's future without her. She noted,

> *"…I just worry about his future. I just always worry about him..... Because [tears up]I know that I'm not always going to be there."*

In discussing her child's next step after graduation, Ms. Cerulean said,

> "*...it's scary for me, because next point is real life*."

Ms. Green's fears were due to what she perceived her child was missing academically and socially. She noted:

> " *I'm afraid. I'm afraid, because, I'm afraid she doesn't have what she needs. Her social skills aren't that great, her ability to...to… common sense, I don't know, it's not very well, I don't think it's good. If I'm gone who's going to take care of you guys? That's it, nobody's going to drive you guys, nobody's going to take you to appointments. Nobody's going to take you nowhere, food, you know, shampoo, everything essential. It's just me."*

Passing Students Along

A subtheme that consistently emerged in participants' concerns was the notion that their children were being passed along. When advocating for the needs of their children, participants cited a frequent concern of a lack of academic rigor for their children. Parent's touted skepticism in a school's push for academic standards for their children. This manifested in the belief of students being passed to the next grade year after year regardless of their skill level and minimal efforts being put into their children's academic success. Because of this belief, Mr. Purple shared the importance of being present within the school when he shared:

"That's why I show up. If you're not involved, they will pass that child through."

Ms. Pink described her experience with children with behavioral challenges.

"I feel like they push children through the system a little bit. I've seen children with behavioral issues that I feel like, yeah, they act out, but it's not because it's an actual problem or an emotional disorder, but they just want attention or they're crying out for something else that they're not getting, and they just act out. <My son>, when he had behavior issues, where he used to hit and fight, and I never knew why. I was like, "Why are you fighting people? Why?" It's because he didn't have the words or the language to express himself. When you gave him the language and now he's using it, but then his speech is rough sometimes, so you don't understand what he's saying, so he get frustrated and now he want to fight. He wants to protect what's his or what he thinks is his."

Ms. Yellow's experience included her experiences with education professionals copy and pasting information from previous reports. She shared:

"I just did not feel very warm and cozy about the person that evaluated him. I felt she wasn't competent and the reason why I feel that way is because when I first saw paperwork from her, it's like she never really took the time to evaluate my son. Everything just seemed to be cut and paste from his previous IEP on this new one that she was supposed to do. She was supposed to have evaluated <my son> and really all of the information was just whatever was on the previous IEP - that these other people that I was still not happy with did…. I feel like, I'm fighting with these people to keep him in a place where he might have a better chance, but if I weren't, then they wouldn't be."

For Ms. Cerulean, concerns about passing her daughter along came through in her experience with a classroom teacher.

"I think that we shouldn't have had to go through it <the battle to get services on the IEP>. That teacher didn't come back. She ended up not moving to the newest location. I think she literally checked out on my child. She says I was upset, because more than <my daughter> wasn't passing her goal. I said, "No, we're not going to finish this meeting, till you sit here and admit you checked out on my child. Do I need to hit the play button <referring to her secret recording of a previous conversation>?

The goal of education is to provide students with academic skills that will allow students to live a life of opportunity and choice. For parents in this study, that option was

limited due to the children's limited academic exposure. If education is the means to better employability which leads to better finances which leads to a better overall quality of life, parents from low SES communities who have a child with a disability are apt to have fewer choices than their non-disabled peers. These parents represent a different voice in education, a voice that is disappointed not because their child is failing, but because they are passing without learning.

Theme: Navigating the Landmine of Special Education

Queries from the interview protocol that elicited responses for this theme emphasized a parent's experiences in meetings, their interactions with school staff and their comfort level in speaking up when they disagreed. Three subordinate themes emerged detailing the critical role of creating positive relationships (Creating Relationships), making sure their opinions are shared (I Make Myself Heard), and balancing the demands of work and a child with special needs (Balancing the Needs of Their Child with Their Employment).

Creating Relationships

The process of navigating school systems/staff to advocate for their child depended on the parent's ability to forge positive working relationships with the school staff. Forging productive relationships were critical in the parent's ability to gather information, speak up for themselves, and trust information/feedback they received. When discussing their interactions with those who serve their children, relationship quality was determined through the amount of trust held and styles of communication. When trust (more on this in the next section) and communication were neglected, relationships between parents and service providers were strained at best, mistrusting and

oppositional at worst. However, when information was provided frequently, forthrightly, and with ease (more on this in Finding Resources: Why is it so hard), parents described less stress when making decisions about their child. The nature of the relationship between the parent and the school professionals added to or took away from hardships that families presented. Positive relationships described all included a person who relieved pressure from the parent. When discussing these positive interactions, noticeable differences were observed in participants' body language. Parents sat up straighter, smiled and occasionally giggled. Examples of this were noted by Ms. Sienna, Ms. Orange, Ms. Blue, and Ms. Pink.

Ms. Sienna spoke about the relationship she had with her child's previous teacher.

> *"..the teacher before, we actually connected really well due to the fact that she had her own child, her own, you know, with special needs. There are some times where I was getting frustrated and she goes, "Ms. Sienna, you need to calm down. Just breathe, breathe, go to work." I will handle your <child> because sometimes in the mornings <my child> wouldn't want to go in the class. So <the teacher> goes just leave. Just go, I will try to bring <the child> in. So she was a big help."*

Ms. Orange described her experience at a meeting with a school in Montana.

> *"I do remember everyone letting me cut them off whenever I wanted to. I felt like really... This was at <School Name>, it was a different school <than where she is now>. It was before she started kindergarten. I do remember that they were really welcoming and they listened to everything I had to say. Everything that I wrote down that I wanted her to accomplish she did plus more. So it really made me feel that they were taking everything I was saying into consideration when applying their skills to help better <my child>."*

Part of what shaped this view for Ms. Orange is how the school in Montana communicated with her. When providing her with IEP information, she reports:

> *"<At the school> they made a binder for me for their IEP, right before <my daughter> started there. They highlighted everything that they think would be necessary for me to know, the numbers too. Then the whole binder was put together so it was just a lot easier of a manual to refer to, instead of just a stapled book."*

For Ms. Blue and Ms. Pink, their positive relationship with their children's school was defined by their relationships with the schools Special Education Coordinator at each school. In Washington, D.C., schools had one person designated in the school as the Special Education contact. This person scheduled and led meetings and was a singular source of special education information for the parent that was not related to their child's performance in the classroom or discipline decisions such as suspension. In Southern California, parents must rely on a variety of staff members for special education information, such as the teacher, counselor or principal. The only consistent person in Southern California for each parent was the principal, but they were not always the initial or primary contact mentioned. Ms. Blue's relationships with the Special Education Coordinators at her children's schools afforded her the opportunity to not worry about the law or any changes that might impact her child's services. She shared the following,

> *"..the relationships that I have with the special education coordinators <at my children's schools>, is that they always keep me abreast of anything new that may come up. Any type of changes, they let me know. I don't have to <read the parent's rights manual> unless I really ... unless something drastic happens and I feel, "Oh my goodness, let me try to figure out what I need to do." But I've never been in that situation so I've never really felt the need to have to look at it for myself."*

Ms. Pink reflected positively on her experiences with both of her children's schools when she attended IEP meetings. This was attributed to "*if any changes ever happen, they always point them out. They always talk about them*."

Contrasting the positive experience of parents with positive relationships, negative relationships yielded adverse sentiments about their interactions with staff when navigating the special education process. While negative relationships caused Mr. Purple

to be cautious with how he interacted with the staff, Ms. Yellow and Ms. Cerulean resorted to strategies that are customarily regarded adversarial by schools.

Mr. Purple reports,

> *" You have to be very tactful with the way you talk. Because I need y'all. Y'all don't need me. So I have to be very tactful in how I ask for you guys ... Even when you guys do things that's wrong, or things I don't like…..um, not wrong, but things I don't like .... I have to be very tactful because at the end of the day, I'm not here, so you know, I mean, I could have good intentions, but just actually run away, then all you got to do is the bare minimum. And if you do the bare minimum, you did your job. So you going to get the minimum."*

Ms. Yellow, described how it feels when asking the school to provide the services recommended in the psychological examination of her son after winning a due process hearing against the school. She feels her relationship with the school declined once she won a due process hearing against the school awarding her son a dedicated aide.

> *"It's very frustrating to me because I almost feel like everybody is still kind of butt hurt over the whole due process, especially the principal because he sat there and I guess they were trying to prove that he wasn't autistic. I don't think I suffer from stress or anxiety until I have to meet these people <the IEP team>, until I have something to do with their IEPs because I feel like, "Oh my gosh, I really need to know and get as much information as I can about what's going on. Otherwise these people are just going to try and take away <services> instead of giving him help. I almost feel like I'm being attacked because I'm just trying to help my kid, advocate for my kid so that he gets these services and he's <the principal> trying to say, "Okay, well he's dozing off and not paying attention <in class>, not because he needs it or it's like a stimulating thing for him, it's because he's not smart." Not in those words, but that's pretty much. I feel almost attacked, whatever services he has, they're trying to take away. I just don't feel like these people are trying to help my son. It's almost like they're mad at us <because they lost at the hearing>. I mean this whole thing cost them a lot of money and it's still costing them because keeping that aid that they don't think he needs because he doesn't have a lot of those behaviors that normally would qualify somebody to have a behavior aid. "*

For Ms. Cerulean, her relationship declined with her daughter's teacher when she felt the teacher had "checked out" on her daughter in a conversation. This led Ms. Cerulean to secretly tape record a conversation with the teacher without the teacher's knowledge,

then contact the school district to complain about the teacher. Prior to calling the school district, Ms. Cerulean did not contact the school principal to discuss her concerns about the teacher. She shared the following,

> *"Long story short, she didn't know I taped her <the school teacher>, so I called downtown, and told them I had the tape and she's checking out. We had a new IEP meeting and we tweaked it again….I think that we shouldn't have had to go through it. That teacher didn't come back <the next year>. She ended up not moving to the newest location. I think she literally checked out on my child. She says I was upset, because more than <my child> wasn't passing her goal. I said, "No, we're not going to finish this meeting, till you sit here and admit you checked out on my child. Do I need to hit the play button?"*

The sole purpose of a professional relationship is to get work done. For parents from low SES communities, the experience of navigating special education is more than getting the work done because "the work" is their child. The parent's responses illuminate the discrepancy in how viewing children as work products rather than individuals working towards a life absent of constraints and the ability to direct their own activities deteriorates the working professional relationship. Absent trust and sincere communication between education professionals and the parent, the experience of navigating the special education system ranges from daunting to disparaging.

I Make Myself Heard

Given the concerns parents had about their children and tensions felt when advocating for their children, it was important to determine if parents ever experienced moments when they did not speak up for something. All but one parent stated they always speak up. Many laughed aloud while saying "No, I always speak up." The parent that did not express this sentiment did not show to meetings due to her conflicting work schedule. Four parents summarize the responses about speaking up for their child's needs.

Ms. Cerulean reflected on her own style of speaking up for her child's needs to ensure she leaves meetings without questions. She shared:

> *"I'm that type of parent. When I come, I come to represent my child. If there's any questions, well, at least twice our meetings have went past time. Hey, it is what it is… that's not my issue. That's yours, so I'm sitting here, asking whatever questions, because when I leave the meeting I would like to leave the meeting with a clear head, and if I did have questions, to come back and ask you, whatever questions, but my thing is to represent my child and be the advocate, and to find out as much as I can, so that I can do whatever research I need to do on the outside or together with you guys."*

Other parents described themselves through analogies such as "Mama Bear" and "the Hulk" to express the experience of speaking up for their children. For Ms. Blue, describing herself as "mama bear", implying her protective nature over her children, was how she described her experience speaking up for her children.

> *"Y'all do not want mama bear to come out." Mama bear has had to surface herself a few times. Once mama bear had did her little growls, everything's been okay."*

For Ms. Sienna, her style of speaking up included describing herself as "the Hulk". She shared:

> *"Your mom is over here coming full force like the Hulk, the green monster. So I guess that's how I get when I get upset, trying to protect my kids."*

Mr. Purple simply expressed the importance of sharing concerns about his children.

"*A quiet mouth not gonna get fed*."

The themes of speaking up is important to note because there could be an assumption that parents from low SES communities are not speaking up for the rights of their children's special education needs. The results of this study indicate that parents regularly speak up when advocating for their child's special education needs, but may do so at the detriment of not speaking up for themselves as discussed in the section I Put

Myself on the Back Burner. This is noteworthy given the findings of the assumptions parents are forced to address while navigating the special education process.

Balancing My Parenting Responsibilities When At Work

When navigating the special education process for their children, balancing supporting their child and their professional responsibilities at work was an added pressure, especially when coping with the specific needs of their child's disability.

For Ms. Green, she was unable to attend IEP meetings due to her work schedule. She had not attended an IEP meeting, since three years ago when her son was first identified for special education services. When describing helping her son with his homework she notes:

> *"I work from 2:00 to 10:00, the swing shift. The <afterschool teacher> told me that he hides his homework…. oh god, it's just such a hard time. I have a very hard time. I would get home and it wouldn't be done. I would get home at 10:00 o'clock, after working a late night and we'd struggle through trying to do his homework. It's just very hard."*

For Ms. Orange, when her daughter, who is diagnosed with Autism, has a behavior outburst or refuses to get on the school bus to go home, she is called to come pick her up from her job. She works approximately 45 minutes from the school. She explains that her boss is flexible and understanding, but worries about her job. She notes,

> *"That's why I was getting frustrated a little bit because I'm like okay, this has got to stop. I can't leave <my work > to come to <the school> to go back to <my work > to come back to < the care giver>, to come back to <home > all in one day. It's like when am I going to work for?"*

Ms. Cerulean uses her lunch break to assist her daughter to obtain her 40 hours of volunteer service to graduate. She reflected on a conversation with her daughter:

> "*Do you understand how you got your 40 hours of volunteer done this summer, and I did it on my lunch break? Do you understand that they allow me to make your hours just upon meeting your mom? This was what you needed. I didn't need*

it. I could've ate, so I'm leaving work, going home, get her, dropping her at the church, then back to work."

Overall, the lived experience of parents from low SES communities when navigating special education systems is complex. It is important for education professionals to establish positive relationships with parents and to acknowledge that they are balancing more than just their parental duties. By treating parents as equals and addressing their actual concerns, educators will create fewer adversarial and intimidating experiences for parents of children with disabilities.

Theme: Isolation/Self-Reliance

Thus far themes one and two have described parental experiences associated with the responsibilities of parenting, working, coping with assumptions about them or their child and competing life events as they make decisions about their child's special education needs. The next two themes will detail the emotional toll these factors take in the participants lives and illuminate the complex array of additional pressures parents from low SES communities must also navigate**.**

I Put Myself On the Back Burner

The participants expressed feeling alone in their ability to share the challenges of raising a child with a disability with anyone outside of themselves. Because of the inability to rely on others to assist in the care of their child, they endured feeling alone when needing to cope with the emotional or physical demands of parenting. Three parents summarized this experience and related theme well. Each described their isolation and self-reliance through reflections on family support, putting their needs last at an expense to their well-being, and failure to provide for their child's needs.

Ms. Yellow describes how the lack of family support impacts her. She stated:

"I just don't feel like my family understands. And even if they were to understand, I've never got that feeling that they're... It's going to... Nobody's ever said it's going to be okay. Nobody in my family has ever said, it is going to be okay. I feel like I almost have to find something that makes me feel better. ….I wish I could have just, been in my little cave crying until I felt better, but I really didn't have that luxury. But I almost feel like everybody else is going to be okay, but I have to get my crap together and be okay because he really needs me to try and figure things out for him. I don't know if that's just me, being extra as my kids say, or I really do need to be this way and just always try and see how we can help him."

Ms. Cerulean describes how supporting her child means putting her needs last, even if it is at her own peril. She shared:

"I feel like I can afford to push myself to the back burner in order to push her forward. Now, how long I could do that I don't know, but I have to, in my parental world, do that, because I feel like I can't sacrifice her. This is a mean world, so I have to make sure she has whatever tools and then I'll come back to me, and that's just the way that is."

When talking to her child's teacher about missed assignments, Ms. Sienna reported,

"*I told him the only thing I could do is I could talk to <my child>, but I can't sit down with <my child> and you know, and guide <my child> through the whole thing. Cause I have my own job. I have to work to support these kids. If mom doesn't work, food doesn't get bought, you know, we're going to be homeless. You know, bills are not going to get paid. So it's hard on me, honestly. It's hard. And I'm surprised I haven't went to, you know, the hospital for a heart attack."*

Based on the participant's response, when navigating the special education process, parents from low SES communities are balancing multiple priorities while supporting their child with special needs. Education professionals can assist parents in their decision-making process, particularly when they are overwhelmed, by responding to their needs with kindness and understanding rather than with judgement and disparagement.

Theme: Extenuating Circumstances

You Don't Know My Full Story

The pressure to be knowledgeable of their child's disability, make decisions based on what they know and educate others about their child's ability amidst a group of people who may or may not assume the least capability in their child is a substantial weight for parents of children with disabilities. For those in low SES communities, it was compounded by a lack of additional resources. Something as simple as the inability to hire a babysitter when family was unwilling to assist, meant that parents had to be the primary provider for everything often at the expense to their own emotional, physical and mental well-being.

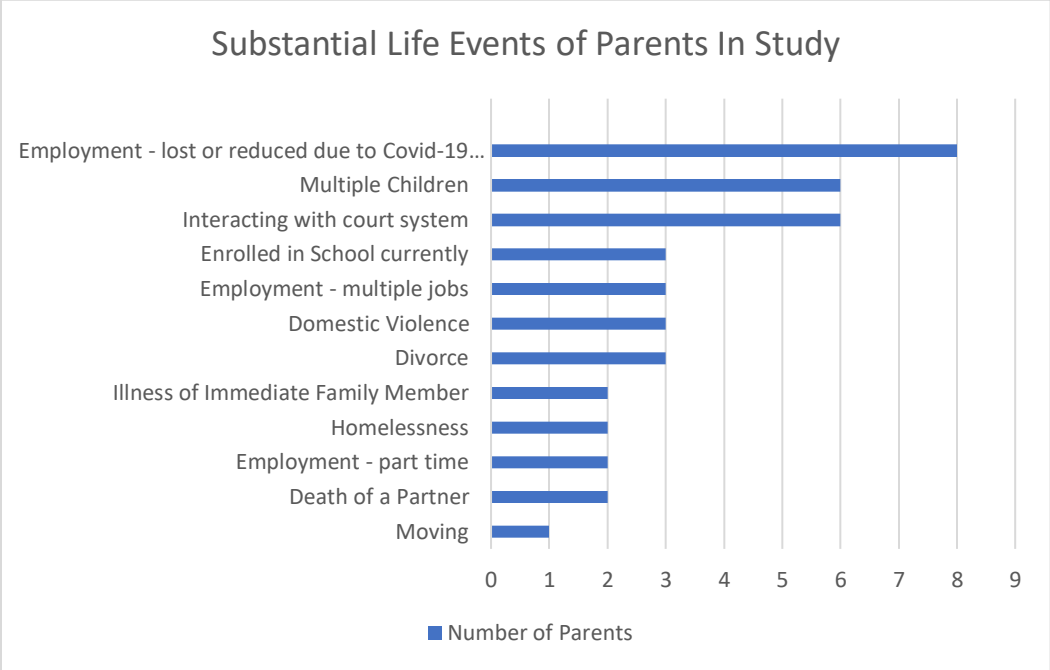
Additional weights for parents were their personal circumstances. Every parent in the study described significant stressful life events ranging from homelessness to domestic violence that led to incarceration of their partner. Six of the nine parents were actively involved with the court system at the time of their interviews. Table 9 demonstrates the significant life events parents had to navigate while simultaneously supporting their child with a disability. Given this, as discussed in Chapter Two, to fully understand the totality of what parents are asked to do when asked to make an informed decision about the education of their child with a disability, it is important to understand the intersection between environment and educational attainment of the parent and how these dueling forces shape their decision-making capacity.

For each parent, these personal experiences were not limited to one event per family. Every parent was coping with multiple significant external life experiences while supporting their child with special needs. An example of this is best summarized by Ms. Cerulean when she shared,

"I juggled two households. I juggled a mother with Alzheimer's, heart failure, high blood pressure, workers that came in during the day making sure they did what they was supposed to, a sister that did not do what she was supposed to, who was in charge of it before I got involved. The sister didn't like that I got involved, because then I found out she wasn't doing what she was supposed to do. She did some dirty stuff."

Table 9

Substantial Life Events of Parents in Study



When describing the emotional impact of these experiences, parents shared the following.

Ms. Sienna noted,

"It's just a lot of people don't understand why I get pissy and upset when I do, and I lash out the way I do because they don't know my story."

When detailing the separation from her husband, Ms. Blue reflected,

"Well I let go when I was ready, when I was strong enough and I just got to the point that I was like, you know what, this is useless. It ain't working. We're living in two different places and da-da this and da-da that. I was like, I'm done. It was at one point I was trying to, because all of my children have the same father, and trying to bring your kids up in a two parent household - but only one parent is present was very...<she pauses and looks down>... That's why I say some things I don't remember because there was so many things outside of that I've had to deal

with that a lot of good things, some good things that I don't remember because it's just remembering those things may trigger something else and you know what, just forget it all."

For Ms. Orange, the tough times were so difficult, they became overwhelmingly isolating. She shared the following:

"Here's the thing, sometimes it's hard for a person when they're going through a lot to reach out to other people. So over this past year, it has been really difficult for me."

Based on these responses from participants, the additional pressure to manage significant life changing events while navigating the special education system adds a significant mental and emotional burden on parents from low SES communities.

Theme: Communication

Communication was identified as a superordinate theme in every parent's response. When examining the role of communication in the parents' experience, two central factors developed: *how* we communicate with the parent is as important as the *what* is said. For some, the mode of communication used mattered (i.e., texting, face-to-face, email, etc.), while for others it was the microaggressions that made the parent "feel" dismissed or disregarded in the interaction.

How You Talk to Me Matters: Use A Method That Works for Me

When discussing the method of communication, parents were clear about the mode of communication they wanted to use to convey important information with school officials, and shared their frustrations when their requests were not adhered to. Two parents notably captured the essence of what other participants shared in their responses. Ms. Cerulean described microaggressions in her experience with the school. She stated,

"*I told the supervisor, we had a new IEP specialist. I kept telling her I need to speak with her, because there are several things I need to know, she needs to*

know, about my child. The lady kept wanting to email. Didn't I say speak? I said speak. I didn't say email me. So I spoke with her boss. She [the IEP specialist] sent me another email and said, "I've spoken with my boss. I've tried to reach out to you by email." [Ms. Cerulean shakes her head in frustration] I said, speak. What part of that don't [she] understand? ……. To me she was playing games, because I wanted to speak with her, tell her what the experience was last year, what I needed as a parent and just to have a simple conversation. You get more from a conversation than you do from an email. ….It just puts the more personal touch, so you know that mom is more involved."

Ms. Sienna also shared her frustrations with email. She stated,

"When it comes to <the principal and vice principal>, it's hard for me to get my questions answered because of the fact that their like, "Oh, email, email, email," and I'm like, "Why can't we just set up an appointment so I could sit down. I could tell you my feedback and ask you a couple of questions and just answer my questions and then that's it? Why do I have to email you? If I'm concerned with something, can't we just set up an appointment?" I….. don't like emails because I feel like there's no connection with an email. There's a lot of confusion with an email. There's things that might get typed that that other person might take the wrong way. It's like a text. Contacting somebody and somebody might take it the wrong way, but I didn't text it like that."

How You Communicate with Me Determines Our Working Relationship

The second theme to emerge about communication was the *what* – what you say to me, the words you use to respond to me shape my working relationship with you. Parents responses illuminated indifferent or flippant responses from school staff that adversely shaped their attitudes. Ms. Orange's daughter was struggling with getting on the school bus each day both in the morning and in the evenings. She reported,

"I had to call the office and they're kind of passive on a lot of things. When I do call, I feel like they try to make me feel like it's the parent's fault with everything… When I asked for another IEP [meeting] because she wasn't getting on the bus again, I feel like I was just referred to you <the researcher>."

Ms. Yellow wanted to ensure her son would be in a general education class for the upcoming school year. She recounted her conversation with the classroom teacher where she felt belittled and inconsequential:

> "*One day I asked her, "We have to enroll him in a kindergarten [class] and I do not want him in this class, so what do I have to do to make sure that he's in a general ed class? And she just told me, "Everything is going to be done through the IEP. You can just sit there and twiddle your thumbs."*

Ms. Red, a bilingual parent, born and raised in Mexico, is a native Spanish speaker. Although she has grammatical errors when speaking English, she is intelligible to a native English speaker. She expressed problems with the communication with the school by describing how a teacher refused to listen to her requests. Below is an excerpt from her conversation with her daughter's teacher when scheduling a meeting.

> *"<teacher says.> 'Oh, you speak Spanish right?' <Ms. Red says> "We're like yeah, that's my first language." <teacher says> 'Oh, so do you need translator?' <Ms. Red says> And I was like no, I don't think so. <teacher says>'Well, I'm going to request a translator for you. For you feeling like better.' And I was offended."*

Based on these experiences, communication – both verbal and nonverbal - between parents and school professionals is central in forming positive and effective relationships for the sake of the children. However, these quotes illustrate how the ability to communicate in an effective manner, in a variety of contexts, with a group of people from diverse backgrounds can be difficult. The needs of the parental population from low SES communities are wide ranging, yet simultaneously limited.

Theme: Trust

Our Communication Influences My Trust In You

A breakdown in communication between education professionals and the parent impacted the parent's ability to trust the information shared with them about their child. Parents' ability to make informed decisions correlated directly with how they perceived the intentions of the person providing the information. Communication and trust were irrefutably interconnected. If the parent did not trust the intention of the person or the

person's commitment to their child, trust was limited. Throughout the interviews, participants described incidents where they did not trust the education professionals. Ms. Yellow described her attorney and how she felt he was hiding things from her. She stated:

> *"I feel like there's a lot of things that he's not going to tell me. I mean plain and simple, one day he told me, it's almost like it's not to his benefit that the school agrees to do these things that they're supposed to be doing….. If they do what they're supposed to, then like everybody else, they've got to eat. Right? So if you go in there and you fight for something that they did wrong and I win, then he's going to get paid. So it's not to his benefit that they do what they're supposed to do. But I thought to myself like, I'm going to give these people a chance because I don't want to have to go through that process. I want my kid to get the help that he needs right now. So I'm sorry if you think that them not doing what they're supposed to be doing right now might be able to get you bigger bucks later on, I want my kid to get whatever help he can get right now. So sometimes I feel like he's not telling me everything. But in my mind I'm like…. I feel like I almost have to find stuff as much as I can on my own so that I know, because I'm not interested in getting anybody money. I'm just interested in helping my kid."*

Another example of feeling leery of professionals was expressed by Mr. Purple when he stated,

> *"You have to be on these people because if you're not on them, they will get over."*

Trust and Race Relations

Race also greatly impacted feelings of trust for many of the participants. For participants of African American descent, race impacted their experience and perceptions of veracity of information. Participants from other racial groups did not mention race in their responses in relation with trust. Trust became a relevant issue in situations where the outcome about the parents' needs were invested in, or at minimum contingent on, the other person's actions. Of the four African American parents interviewed, two spoke on race while the interview was being recorded. The other two spoke on race once the recorder was turned off. Both of those parents were overly mindful of the recorder in all

of their responses. At one point, Ms. Cerulean asked that the recorder be turned off because she did not want what she was going to share to be recorded on tape. Although what she shared was a personal story, her demeanor and relaxation changed once the recorder was off and she began to speak freely. The interviewer proceeded to take hand written notes. Two parent's comments summarize the experience shared by the parents of African American descent.

For Ms. Pink, race mattered when it involved the education of her daughter. When discussing why she withdrew her daughter from her previous school and enrolled her in her current school, she mentioned race as a factor for her transfer. Although her current teacher is White, she trusts in her ability to educate her daughter. In her responses she shared,

> *" I don't know if I'm allowed to say this, but it was a predominantly white school, so they ... I don't want to say that because I think it sounds bad. Let's use <her current teacher>. She acts like she's one of us. (laughter) She's cool. She can relate. Then she's younger, so she can relate to me and to <my daughter >. I just think if you've never been around an African American child or you don't know their patterns or their lifestyle or how they grew up or anything, you don't really understand them, you will never understand them, so teaching them is hard. You can have some great teachers, but I've never had education like I had from ….teachers that teach from a background of African descent. Never had that. Never experienced that in my life. …They get you. They know who you are. You vibe together. I don't know another way to explain it."*

For Ms. Blue, race impacted her ability to accept a diagnosis of her daughter. She reported,

> *"So the doctor that evaluated her, deemed her retarded. That I did not agree with, because she's not retarded. She has her own way of learning that's different... Well, because everybody has their own way of learning. Because you have some that can catch things faster than others. And for her, you may have to reword something, and then she'll be like, "Oh, okay, I get it." And sometimes you may have to repeat it just a couple of times, or you may have to show her. Once you show her, she catches on. That's something that I was very disappointed with, but at that time I didn't... I mean, I wanted to make a scene, but I chose to be an adult.*

> *I chose to be an adult, and just like, "Okay, you know what? If that's what you feel... " So that way she'll be taken care of. I understand the fact that she would not be able to live on her own. I accept that. I see that. I don't want to claim that she is retarded, and I won't ever claim it, because the thing was, is, the day that the assessment was done, she was unfamiliar with the person. The person did not take time to warm up to her. Because for one they were a foreigner."*

For the parents in this study the complex concept of trust is comprised of multiple facets. Education professionals can improve trust between them and parents by following through on how parents want to be communicated with and through building positive rapports with parents.

Theme: Trepidation

If I Don't, No One Else Will Fight for My Child

The sadness felt by each parent was clear not only in their words, but also in their actions. Every parent, except Mr. Purple, cried during their interview. The challenge of raising a child with a disability left parents feeling assured in their sentiment that no one else would take the time to care for their child should something happen to them. With uncertain futures and absent support systems, parents experienced all the burdens often at a cost to their own well-being. Three parents summarized this sentiment.

Ms. Cerulean describes the mental, physical and emotional exhaustion felt when all of the responsibility falls upon her, without tending to her own well-being.

> *"I'm frustrated as a parent, because I'm exhausted. I'm mentally and physically exhausted… Because, if I don't make it, she doesn't make it, so therefore I have to be strong to get her through, and then I can think about me, because the fight isn't fair for her."*

Ms. Yellow's despair is palpable when she describes "that nothing's ever going to be easy" while simultaneously acknowledging that if she gives up fighting for her child, her child will have limited opportunities.

> *"Why am I stressed? Why am I feeling this, if I know now I understand now, that if I want him to have any real kind of opportunity, I'm just going to have to fight for him forever. I'm okay with that. So, why am I going through all this <mental stress>? Like mentally if I already know that nothing's ever going to be easy…..It just worries me that I'm going to get tired one day of fighting with people and I'm just going to give up and just whatever. And he's never going to really have that opportunity to one day be responsible for himself and not have to be depending on his brothers or sisters or whatever. I don't know. I feel like what every parent wants for your kid to grow up and have a life that they feel happy with, where they can be productive and just be responsible for themselves. And I feel like if I don't keep fighting for my child, if I finally just give up, then he's not going to have those opportunities."*

Ms. Green's fears centered around feeling as though she had failed her son. She shared:

> *" I think I failed him, and I think yeah, I tried. I don't know what else to do, every day I wake up, "This is so hard." I don't want to give up on him, I don't know what's the next step. It's really hard, I don't know what else to do. I don't want him to be a failure, I don't want him to end up where I'm at*."

For each parent in this study, the challenge of raising children with mental, physical, cognitive or emotional developmental issues that diminished their capacity to be educated in the same manner as their non-disabled peers seemed overwhelming.

Theme: Finding Resources: Why Is It So Hard?

It's Like A Hidden Secret

Questions for this section in the interview protocol addressed where parents seek out information when they are uncertain or have a question about special education and how to make it easier to find information. A noteworthy finding was that parents in Washington, D.C. spoke about going to the Special Education Coordinators at their child's school when seeking information. In this position, one staff member is responsible for special education compliance in the school and serves as a liaison between the school and all families receiving special education services. This position did not exist in the schools in Southern California. Families in Southern California have only the special

education teacher and principal to turn to for questions. Occasionally there was a school counselor, but this was not consistent. This proved challenging for those parents, particularly if they did not get along with the principal or teacher due to breakdowns in communication or trust as previously discussed. Where parents in Southern California went for information was as varied as the possibilities themselves. Although no parent sought out the same resource, what was consistent about each was that the organizations they sought out simplified the process of getting information. Parents also felt that they could trust the information being provided to them. External resources included community-based organizations (i.e., TASC, PAVE <Parents Amplifying Voices in Education>, Harbor Regional Center, Thrive), individuals with special education knowledge not at their child's school and Google. The challenge of finding information was echoed multiple times from the parents in Southern California. When describing trying to reach the school staff, Ms. Sienna notes

> *"It's hard to get the answers because they're always busy. The principal and the counselor, they're always busy. So it's like I cannot ever get through to them. But I don't know. I mean, I don't know. I guess just, she said email them. So I guess through an email I could get my questions answered."*

For others, just trying to find answers was difficult. For Ms. Cerulean, finding help felt like it was a hidden secret. She shared:

> *"Just the resources for the help is my thing. Make the resources accessible and easier to obtain. It's like a hidden secret."*

Like Ms. Yellow, Ms. Red, shared her experience of reaching out to multiple sources to obtain information. She noted:

> *"Well right now I have a lot of information of Schools from PAVE. They gave us the graphics and so the school, their ranking, so that information I have from them. So right now I know that there are some websites on the internet. If I have a question or, for example, I know right now people who having a special*

education. So I, I just contact them and ask them like, you know what, I did this and that and they explain me. For example they had Mr. Monto. He, he, he was the, he was a principal at <an elementary school>. There is an another coworker who had a special ed, a teacher. So I have contact with the two of them mostly. This other girl who has the special education degree I just met her like twice, but I usually been asking to them and, and basically, yeah, that's it. Sometimes I just go to internet and I get upset with the disability and they have like a down syndrome pictures."

Too Many Resources to Organize

Once parents were able to locate information, they were tasked with the responsibility of organizing all of their information from multiple sources. This proved to be an additional challenge for some. Ms. Orange illuminates this when she shared:

"Sometimes there's just so much paperwork. I feel like if there was marked and consolidated and maybe... The binder, I'm going back to that because that was more organized. So instead of a bunch of papers shoved in a backpack, it was like a binder. Then I would see where we left off, what's upcoming the next week. Right now I just felt like it's a mess.

Similarly, Ms. Yellow had multiple pieces of information, but had to go to multiple sources to obtain answers.

"Before, if I had a complaint or something, whatever it was, I would talk to my kid's teacher and we would try to solve it that way. That's how we would try to move forward with whatever we decided. But over here it's like, you talking to the teacher is just pointless because it doesn't matter. You get over here to these IEPs and if you don't bring it up then nothing's happening. I think that's another reason why when I went to the IEPs I was just like, okay, whatever. I just can't wait to get him out of here. Since then I've gotten on websites. So for example, I went on one site I went to meet with this person from TASC. They're the ones that offer different little information sessions on the various different things that are available. Like the information technology thing. They help you know how to navigate an IEP and just a bunch of different little things. So I went and I met with one of these gals and they're so nice. They give you all this information to other websites that can help you with understanding the process and all of these things. So I've gotten on all these other websites and they seem to be so much easier to read. So that's where I go. But really, it just shouldn't be this difficult."

Based on parental responses, finding information to answer their questions about their child's special education needs varies. For schools with a dedicated special

education staffer, that was not involved in grades or discipline, gathering information was easier as exemplified in the quote from Ms. Pink "*if any changes ever happen, they always point them out. They always talk about them*." For schools where the teacher or principal was the central contact, gathering information was more challenging. Factors affecting the acquisition of information included previously discussed themes of trust and relationship building as these factors influenced how parents received the information provided. For parents that did not have a direct resource, extra energy had to be exerted finding resources. Given parents' discussions on time constraints and some parents' limited understanding of their child's disability, the time and background knowledge needed to find support is an added burden in an already overburdened experience. Similar to being aware of how to best communicate with parents, providing the Procedures Manual in different formats may prove helpful for parents to improve their experience when making decisions about their child's special education needs.

Theme: I Don't Know My Rights

Interacting with The Parents Rights and Procedures Manual

Queries in this section of the protocol focused on how parents interact with the Parent's Rights and Procedures Manual. Unanimously parents admitted that they do not read the manual. At best they glanced through it when their child was first found eligible for special education services, however no parent reported actively using or referring to the manual, even the parent with an attorney. Responses to the manual included Ms. Blue's:

> *"Oh, I hate that thing! I was throwing them out. After a while I got turned off to it because I was just getting photocopies of it instead of the actual booklet itself."*

Ms. Red and Ms. Yellow noted adversity to the length and complexity of the manual. Ms. Red shared:

> *"I think I read the first one. I think I just read [it] once because there's so many pages."*

While Ms. Yellow reflected upon the difficulty reading the manual. She shared:

> *"I gave up looking at it. I feel like I'm not a real dumb person when it comes to reading documents. I mean that's what I do all day. But I feel like unless you're familiar with a lot of the stuff in here, I mean I've read this thing because I was so unhappy with the first two years that we had with the district that I tried to read this thing and I thought, oh, my God, am I like the stupidest person on the planet? Like what does this mean? Maybe I am the stupidest person, but I could not figure out some of this crap. I use them now for scratch paper."*

Improving the Manual

Based on parent's limited interaction with the Parent's Rights and Procedures Manual, protocol questions included how school systems could improve the manuals to make them more parent friendly. Responses included suggestions such as making an app, audiobook, putting it online, adding pictures, and highlighting key information. Ms. Green shared why having the manual online would be better for her. She stated:

> *"It's a lot, I mean, online it's much easier, you just skim through it. This <referring to the pamphlet>, you have to open a page, find the index, or table of contents. I'm going to have to look in there, what page, page 10, okay. Online, you just click, click, click, okay I'm here. It's much easier, I think."*

Mr. Purple suggested changing the format to include more graphics. He shared:

> *"I don't want to read it unless I have to. It looks tedious. It looks like all them words to me. If you had some pictures, I might be like, "Okay, so what's cuz doing, man?"*

Ms. Cerulean further expounded on this idea by describing a simpler way to write the manual to make it more accessible. She shared:

> *"I think if they put it, because everybody, maybe wouldn't understand, maybe a little bit more in layman's terms."*

Although only one parent wanted the manual to have a practical application for their children's academics, her statement was noteworthy because when parents were asked what was something they wanted to know more about in special education, all responses were specific to a problem they had at the moment. Ms. Sienna's response summarizes this sentiment.

> *"I think that if they were to explain how they're going to help your children, your child and what are they going to do to help your child in the booklet, then I would probably read it. But this is all legal stuff. Right? So if you don't have a problem, then there's no need to read it. If it explained this is how we're going to help all the special needs children that are in RSP [special education is called RSP in California]. This is how we're going to help them. This is what our goal is, to guide them through this in school time," then it would be a little bit more interesting, and I would take the time to read it."*

Based on parental responses, parents from low SES communities do not utilize the parent's rights and procedures manuals as they were intended due to difficulty accessing the written material. These findings suggest that parents of children with special needs may find the Procedures Manuals difficult to read and comprehend. These findings also suggest that even if parents were able to access the material in the manuals, they may not know how to apply the information in the manuals to their circumstances.

Theme: Covid-19 Pandemic

Loss of Income

It is noteworthy to discuss the impact of the COVID-19 pandemic on the lives of the participants. As of April 10, 2020, most private and public school systems closed nationwide. Participants that were interviewed prior to the pandemic were called to determine the pandemic's impact on them. For the participants of this study, all but one was impacted financially due to pandemic-related job loss or reduction of work hours and

income. As single parents, the participants were at home supporting their children's home learning opportunities. All others lost part of, if not all of their income source.

Distance Learning

In addition to the pressures of lost income, parents in this study were tasked with assisting their children on multiple online platforms to complete assignments. While some struggled accessing platforms, others struggled to support their children completing the assignments. Ms. Green's response captures this sentiment.

> *"I couldn't even get that <assignment>. I was going through different websites trying to understand the concept, I just couldn't get it. A lot of the, what is the other one we had a hard time with? Fractions. Number one fractions, oh my god, I was going through it over and over for an hour. I still couldn't get that."*

Ms. Sienna spoke about the difficulties of supporting multiple children in different virtual classrooms. She noted:

> "*Oh my God, it's too much. My son's Google Classroom is easier. He can do it with no help. He actually shows me what to do. But <my daughter> I can't figure it out. I just quit and honestly we just don't turn in the work."*

Chapter Summary

Chapter Four details the emergent superordinate and subordinate themes that emerged through data analysis. Four questions guided the study to determine parents of low SES lived experience while making decisions about their child's special education needs. The table below illustrates the themes that emerged.

Superordinate Themes	Subordinate Themes
Experiencing my child's disability	a. Medical versus non-medical disabilities b. Assumptions about me/my child c. I just worry about their future d. Passing students along
Navigating the landmine of Special Education	a. Creating relationships b. I make myself heard c. Balancing my parenting responsibilities when at work

Isolation/Self-Reliance	a. I put myself on the back burner
Extenuating Circumstances	a. You don't know my full story
Communication	a. How you talk to me matters: Use a Method that Works for Me b. How you communicate with me determines our working relationship
Trust	a. Our communication influences my trust in you b. Trust and race relations
Trepidation	a. If I don't, no one else will fight for my child
Finding Resources: Why is it so hard?	a. It's like a hidden secret b. Too many resources to organize
I don't know my rights	a. Interacting with the Parents Rights and Procedures Manual b. Improving the Manual
Covid-19 Pandemic	a. Loss of income b. Distance learning

CHAPTER FIVE: DISCUSSION

The purpose of this qualitative phenomenological study was to understand the lived experience of parents of low SES communities and how they experience navigating the special education process for their child with a disability. This chapter includes a discussion of the major findings as related to the literature on poverty, decision-making, parental advocacy, and readability to help answer the research questions that guided this study:

RQ1: How do parents from low SES communities experience their child's disability?

RQ2: What is the essence of the lived experience of parents who live in low SES communities when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?

RQ3: How do the parents from low SES communities interpret their rights and responsibilities in the educational process?

RQ4: How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child(ren) with special education needs?

The chapter concludes with a discussion of the limitations of the study, areas for future research and a brief summary.

Interpretation of the Findings

The Role of Relationships

"Communication and Trust are two main ingredients for a successful RELATIONSHIP."

- *Unknown*

Parent trust is a critical component to manifesting parent school relationships (Adams & Christenson, 1998; Rimm-Kaufman & Pianta, 2005). Parent-teacher relationships have long been considered not only a puzzling problem, but also a potential resource for improving students' school success (Kaplan, 1950; Minke et al.,2014). However, parent-teacher relationships are unusual in that they can be emotionally charged and entered into non-voluntarily. For parents in this study, the emotional work of interacting with school staff was frustrating, burdensome, and at times intimidating. Significant factors in forming positive or negative relationships between parents in the study and education staff depended on the level of communication and trust established between them.

The dynamic nature of these concepts suggests that school-based practices such as effective and culturally responsive communication practices and interpersonal dynamics such as trust are integrated as a part of parents' overall experiences with family-school connections. This study's analysis of the essence of these parents' lived experiences demonstrates the need for engaging in conversations with families around their needs, as

well as in assisting them in their efforts to advocate for their child's special needs. A fundamental finding was that what schools have to do to improve communication with parents is threefold. First, schools must become conscious of the "approaches" they use to communicate with parents. Second, schools must become intentionally conscious of how parents are asked to communicate back with them, and thirdly, schools must become conscious of how/what something is said to parents without assumptions. What emerged from participant's responses was a dichotomy between each parent's passive compliance with educational decisions and learning to become an advocate for their child. Depending on their experiences with family-school communication, parents can feel highs and lows across a continuum about their decision-making capability. Two statements summarized these very different experiences for parents based on their communication experiences. Statements such as Ms. Yellow's make clear the levels of isolation, hopelessness, and disempowerment parents can feel when advocating for their child with special needs.

> *"Why am I stressed? Why am I feeling this, if I know now, I understand now, that if I want him to have any real kind of opportunity, I'm just going to have to fight for him forever. I'm okay with that. So, why am I going through all this <mental stress>? Like mentally if I already know that nothing's ever going to be easy…..It just worries me that I'm going to get tired one day of fighting with people and I'm just going to give up and just whatever. And he's never going to really have that opportunity to one day be responsible for himself and not have to be depending on his brothers or sisters or whatever. I don't know. I feel like what every parent wants - for your kid to grow up and have a life that they feel happy with, where they can be productive and just be responsible for themselves. And I feel like if I don't keep fighting for my child, if I finally just give up, then he's not going to have those opportunities…. It's like everything is a struggle. They don't want to give you anything unless you ask for it. Even then it's like if they can, they won't give it to you."*

However, Ms. Blue's comments depicted how frequent, reliable and open communication can shift the emotions of isolation, hopelessness, and disempowerment

into sentiments of partnership, comfort and empowerment when advocating for their child's needs.

"I think, for one, is the relationships that I have with the special education coordinators, that they always keep me abreast of anything new that may come up. Any type of changes, they let me know. I don't have to unless I really ...unless something drastic happens and I feel, "Oh my goodness, let me try to figure out what I need to do." But I've never been in that situation so I've never really felt the need to have to look at <the procedures manual> for myself."

A second important factor to consider about communication is the difference between print culture and oral culture. As discussed in Chapter 2, to be successful in navigating the world of education, families of lower SES communities have to overcome at least two main obstacles: first, learning the language of the middle class (Beegle, 2003; Ong, 1982), and second, learning the communication styles of the middle class, as both are the dominant language of school systems (Beegle, 2003; Ong, 1982). Walter Ong (1982; 2013) found that most people living in poverty demonstrate characteristics of *oral culture* through which they obtain information primarily verbally. He describes oral culture as spontaneous, relationship-based, and strongly associated with emotions and physical touch. Conversely, in *print culture,* individuals obtain their information primarily from print and tend to be individualistic, linear, analytical and focused (Beegle, 2003, Ong, 1982). When parents and students of lower SES communities enter the world of education, there is often a mismatch in communication styles, as individuals with lower levels of education and use of oral culture encounter the formal style of print culture prevalent in the U.S. education system (Beegle, 2003). The mismatch in communication styles was clearly a barrier for parents in this study as they navigated the special education process to make the best decisions possible for their child. Ms. Sienna's statement reflected this best when she said:

"I actually like meeting with people face-to-face. I don't like emails because it's just- there's no, I feel like there's no connection with an email. There's a lot of confusion with an email. There's things that might get typed that, that the other person might take the wrong way. It's like a text. Contacting somebody and somebody might take it the wrong way, but I didn't text it like that. You see what I'm saying?"

While it might be easy to recommend that parents from low SES communities learn middle class language and communication styles, such a recommendation shifts responsibility onto the parent rather than onto the service provider. Although learning the norms of middle class language and customs that dominate education would be helpful, given the additional challenges parents from low SES communities may be facing within the family or personally, this becomes one more hurdle for parents to overcome before they can fully engage in successful advocacy for their child's special education needs.

Emotionally, parents in the study reported feelings of being overwhelmed. Caring for a child with a disability, particularly when the child's behavior is difficult or when their needs are challenging, may leave parents feeling cut off from support systems and perceiving a lack of empathy from others. For parents in this study, the emotions were raw. All but one participant cried while sharing their experiences. What stood out most in these interviews was a similar facial expression from each parent – an expression I have seen multiple times as an educator and now understand that I have misread. Each parent's facial demeanor was stoic and matter of fact, almost angry and antagonistic. As I listened to each parent's experience and observed their behavior, I learned that the expression represented a parent trying to maintain their composure as they discussed the school-related experiences parents of children with disabilities experience every day. For them, the experience of caring for their child's special needs were significant and, at times, overwhelming. It was not until they were able to share this experience that the matter-of-

fact veneer cracked, and a release of these emotions occurred. It was as though the act of my questioning and listening was cathartic, even though I offered no solutions to their problems.

These responses suggest not only the need for improved listening to parental concerns but also the need for parents to consider respite care stratagems and for communities to support them in this endeavor. In each of the parent's experiences, great emphasis was placed on advocating for services for their child. Based on their responses and the toll caring for their child with special needs has taken on their social emotional well-being, equal consideration is needed in looking for respite care stratagems to support their own social emotional needs. The consistent emotional response of tears reinforces that education professionals need to view parents beyond their school policies and procedures and as people who are attempting to navigate multiple challenging personal and familial situations. An increase in empathy and understanding of parents' lived experiences may improve parental well-being and foster more conducive relationships between parents and education professionals.

Trust and Race

While levels of trust were forged in the "ways" or "hows" of communication between parent and education professionals, trust and race became a powerful subordinate theme that manifested from the interviews. Of the nine parents interviewed, four were of African-American descent. Each of the African American parents described a distrust of education professionals serving their child, either through testing or teaching, based on race. The distrust expressed by each parent centered around the parents' beliefs that a lack of understanding of their culture impacted the non-African American

professional's ability to connect with and understand their child. The parents perceived this inability to connect manifested in the child not performing at their full capacity, at best, or not performing at all, at worst. Either way, the parents perceived that racialized misunderstandings resulted in a misrepresentation of the child's true capability.

Research data demonstrates that African American students do not fare well academically, socially, or behaviorally when compared to their White, non-Hispanic peers (Brandon & Brown, 2009; Wolfe & Duran, 2013). While it is widely accepted that parental attitudes, behaviors and activity related to their child's education influences their child's learning and educational success, the parent's responses provoke the question of how does *who* serves an African American child impact parental involvement in their academic years? While none of the parents appeared to be uninvolved in their child's academics, how each parent of African American descent behaved with school personnel was notably different from the others interviewed in the study. Ms. Cerulean tape recorded a meeting with the teacher without her knowledge, then used the threat of playing the recording when she needed a different level of commitment from the teacher towards her child. Mr. Purple was hypervigilant in how he spoke to school officials, being cautious not to offend. Ms. Pink withdrew her daughter from a predominantly white school because she did not trust the education her daughter was receiving from white teachers. Although her daughter's current teacher is white, she deemed her "cool" because she could relate to the African American culture, yet acknowledged the importance of people who "get you culturally" and the difficulty in learning from someone that does not understand you culturally, primarily due to their misreading of a different culture's actions. If we accept the bidirectional relationship between parental

attitudes, behaviors and activity related to their child's education influencing their child's learning and educational success, we must ask if African American parents deem culture a liability in their child's education, regardless of disability status? More research needed in this area is described in the recommendations section.

Barriers to Parental Advocacy

While it was clear from this study's findings that communication, trust, and limited transparency in available options for their child, impact the experiences of relationships between parents from low SES communities and education professionals, how communication and trust intersect determines the level of barriers experienced by parents from low SES communities when navigating the special education process for their children. The following sections detail the barriers that impact the success of parental advocacy for the low income parents in this study when navigating special education.

Disability Ambassadors

Some parents experienced having their child's disability being viewed as a homogenous experience, as though every child with a particular disability has the same outcome, rather than through their child's unique individual traits, abilities and experiences. Examples of this included the experiences of Ms. Red whose daughter is diagnosed with Down Syndrome, and Ms. Yellow whose son is diagnosed with Autism. How people view their child's disability impacted not only how people viewed the child, but also the parent. This was connected to how these parents interpreted their parental self-identity. Rather than "only" being advocates for their child, parents of children with disabilities must also become disability ambassadors that educate everyone they

encounter, regardless of their actual knowledge capacity or ability to apply what they know to a larger context.

The regular and repeated exposure to the microaggressions associated with assumptions made about parents and their child exposes similar symptoms as those experiencing severe trauma/toxic stress as outlined in Chapter 2. When describing these experiences, each participants' voice level increased to an agitated tone, hands were used in gesturing, pointing or slicing manners to emphasize points and shoulders tightened about their necks. Based on their physical and verbal responses when retelling these experiences, the emotional load of educating those around them, be it professionals, family, or strangers, increased the onus of educating others on the parent, rather than those around them taking responsibility to educate themselves. In these cases, a marginalized group (the parents of children with a disability from low SES communities) are tasked with becoming educators about a disability they may not feel able to articulate fully, in terms of how or to what extent the disability affects their child. While simultaneously trying to advocate for their child's educational needs, parents from low SES communities are expected to be patient and polite disability (and at times, race) ambassadors who educate others on how to think critically about disability and its causes. Such a role requires them to unselfishly engage in questions, assumptions and doubts from others who may have multiple opinions about the topic/their experience, but have spent limited time if any in that parent's actual experience. The findings of this study indicated that this emotional labor was an extraordinary burden.

Othering

At times, parents shared experiences that reflected their advocacy skills and sense of empowerment as they found ways to support their child's educational needs. Yet in other stories, they described an experience of being "othered" where decisions were made for them or around them. An example of this is seen when Ms. Yellow asked about her son's class placement for the upcoming year, and was told that the decision not only will be made at the meeting, but that she can come and "twiddle her thumbs" during the discussion. Such statements indicate inaccurate and harmful assumptions of the parent's education values and desire to have meaningful input in their child's learning experiences.

Not Knowing How to Effectively Speak Up

Unfortunately, parents of children with special needs may come to an IEP meeting and feel overwhelmed or threatened by the very team responsible for providing their child with a safe and nurturing learning environment (Wellner, 2012). Past research findings that parents feel intimidated and mistrustful of the professionals at educational meetings (Smith et al, 2006) were supported by the experiences shared by the participants in this study. Parent's perceptions that in order for their child to receive special education services, they must accept the conditions recommended by the school system, placed school officials and parents at odds. Of the nine participants, only one sought legal counsel. The others all stated they had no problems with the outcomes of the IEP meetings, but through further discussion shared multiple areas of concerns that should have been addressed at an IEP meeting, including feeling that their children were not getting the education they needed to be successful. For some families, exemplified in the experiences of Ms. Cerulean's late autism diagnosis of her daughter, Ms. Blue's ID

diagnosis of her daughter, Ms. Yellow's request for an aide and Ms. Red's request for continued placement in the general education school building, this is not an acceptable compromise and may thus create further distance between parents and the educational system. The cracked relationships forged between the parents and education professionals were reflections of the broken trust and communications with education professionals.

Although parents were clear to express their viewpoints to school officials, it did not lead to the desired outcomes they hoped for in each of their personal experiences with their children, as noted by Ms. Orange who needed to get her daughter on the school bus, or with Ms. Cerulean who wanted to know more about which services were available for her daughter after her new autism diagnosis. Both of these parents were adamant about ensuring the school staff heard their concerns, yet neither was able to effectively utilize their voice to obtain needed services for their children. Both scenarios demonstrated situations where parents can find themselves in meetings where they are asked to provide input, but are at a disadvantage when they lack the expertise and knowledge of the trained professionals at the table.

Similar to the findings of the 2010 study conducted by Audrey Trainor, parents she would have identified as "The Intuitive Advocate" in this current study, discussed their children through their relationship with their children. Examples included describing their children based on their ability to "manipulate" them to get what they wanted (Mr. Purple) or through the child's ability to open an app independently that was unfamiliar to the parent (Ms. Orange). Based on these "attributes", parents described their child as being capable of doing more than what others assumed of them. Similar to the discussions about what parents knew about their child's disability and how parents were

able to describe how the disability impacted their child's learning, parents whose child had a medical component were able to describe their child's disability and its impact with a measure of expertise. They were also more successful in advocating for their child's needs. In her study, Audrey Trainor identified these parents as "The Disability Expert Advocate."

Disability Expert Advocates, such as Ms. Yes (whose son has autism and genetic disorder) and Ms. Pink (whose daughter is hearing impaired), were more astute at navigating the special education system. For Ms. Yes, she procured a dedicated aide for her son. Although she was unhappy with what she calls "the battle" to get the aide, she was nonetheless successful in obtaining an aide for her son. Ms. Pink successfully enrolled her daughter in a program for the deaf and hard of hearing, and she is happy with the quality of teaching her daughter receives.

Intuitive Advocates such as Ms. Orange and Ms. Cerulean, who described their children in terms of their relationship with them, have been less successful in advocating for their child's needs. Ms. Orange, who was unable to articulate how autism impacts her daughter, has been unsuccessful in partnering with the school to get her daughter on the school bus each day. Ms. Cerulean, who was unable to describe her daughter's disability, has been unable to obtain ABA services for her daughter.

Given the experiences of my participants, past research that has indicated major components contributing to parental confidence and willingness to advocate for their children such as creating positive relationships with teachers and professionals (Blue-Banning et al., 2004; Hess et al., 2006, Trainor 2010), and access to information about the special education process, rights and responsibilities included in IDEA (Leiter &

Krauss-Wyngaarden, 2004) is on target and provides valuable insights to improve the experiences of parents from low SES communities when navigating the special education process to advocate for their child.

Personal Setbacks

Personal circumstances were another source of additional barriers for parents. Every parent described significant stressful life events, ranging from homelessness to domestic violence that led to incarceration of their partner. Historically, individuals who are poor live in substandard housing, are more likely to have unsafe/dangerous jobs and live in areas where there is a high probability they will experience or witness violence (Groce et al., 2011). Given this, as discussed in Chapter 2, to fully understand the totality of what parents are asked to do when asked to make an informed decision about the education of their child with a disability, it is important to understand the intersection between environment and educational attainment of the parent and how these dueling forces shape their decision-making capacity. Given the neurological and biological effects of poverty, it is possible that parents too are experiencing challenges similar to those of their child with special needs.

Using and Gathering Information

An additional barrier for parents in the study to successful navigation of the special education system was how they utilized the information they had to solve the problems they encountered. This can be explained through the theoretical framework used in this study, the Heuristics and Biases Framework and it's heuristic strategy of "category-based judgements" (Bruner, 1957).

The heuristic strategy of "category-based judgements" occurs when individuals simplify their understanding of the environment by relying on knowledge of a particular category or class of information to arrive at a conclusion about a particular topic. This strategy was evident for parents in the study. Two examples of this included Ms. Cerulean and Ms. Orange. For both parents, when struggling to obtain a desired result from the school for their children, both resorted to calling someone they identified as a supervisor. Both assumed that because they had called a supervisor, their requests would be taken seriously by school professionals. However, when asked if they could verify that a supervisor had spoken to the people they complained about, neither was able to confirm their actions had been successful. They both assumed additional conversations had occurred between the supervisors and the offending staff because the offending staff member spoke to them more tolerably in their next encounter. Although neither of their problems had been resolved, they interpreted the outcome of having a different type of interaction as evidence that their complaint to a supervisor was successful and that they were to be taken seriously by school officials.

This construal was also seen when parents made decisions based on race. However, it is noteworthy to mention that the application of this construal in the parents' decision-making process is not to take away from the mistrust observed by African American parents of non-African American education professionals. The intersection of how trust and race impact one another continues to warrant further exploration. Two examples of category-based judgements based on race were evident in conversations with Ms. Pink and Ms. Blue.

For Ms. Pink, she withdrew her daughter from a school because the school had too many white students and teachers, only to enroll her in a class of predominantly African American students, but with another White teacher. Her assumption was that her daughter would receive a better education from someone of the same race. She did not factor in the school's test scores, resources, level of learning in the classroom, teacher attributes or teacher attentiveness to her child's specific learning needs. When Ms. Blue was told that her daughter was diagnosed with an intellectual disability, she refuted the diagnosis because the examiner was from a different country. Although she acknowledged that at the age of 15 her daughter is unable to ride a bus by herself and will never be able to live on her own, she will not acknowledge that she has an intellectual disability. Rather than identifying the criteria needed to qualify for an intellectual disability and forming an opinion based on what she already acknowledges about her daughter's capabilities and how that compares to the criteria of an intellectual disability, she rejected the diagnosis because the examiner was from a different country.

In at least one instance, this construal was applied to the Parent's Rights and Procedures Manual. Ms. Sienna remarked that she did not read the manual because she thought it was only relevant if she had a legal problem. For her, legal equated to the need for a lawyer and court. Thus, if she did not have a legal problem, there was no rationale to review the procedures manual. Although Ms. Sienna did not express a current concern that involved services for her child, her logic of only needing the manual once she had a legal concern was an inaccurate application of knowledge about why she would need the manual.

Successful Navigation of the Special Education System

It is noteworthy that despite multiple barriers impacting a positive experience navigating the special education process, there were some positive outcomes discussed by parents. When parents detailed successful experiences navigating special education, they described ease of obtaining information. For Ms. Orange, it was through a binder assembled by the school that organized all pertinent special education material for her. This made finding important documents and numbers easier for her. For others, especially those in Washington, D.C., it was having a reachable contact that could answer their questions, for example, the Special Education Coordinator/Director. Because a lack of time was often mentioned in each interview, making information/answers easy to find was key to improving the experience of navigating the special education process for parents in the study.

Ineffective Procedural Safeguards

Another barrier impacting effective parental decision making for their child's special education needs was an inaccessible procedural safeguards manual. Each of the manuals used in the study were written in a manner that made them too complex for parents to access in meaningful ways. None of the participants in the study utilized the manual for their needs, regardless of their state, D.C. or Southern California. Parents were frustrated with the manual's legal jargon, technical detail, appearance and length. Had parents been able to adequately access the material in the manual, at least three would have been able to solve their problems through an IEP meeting or a due process hearing. Although due process hearings are an important tool for parents when making decisions for their children, it is noteworthy to mention that they may be viewed as overtly adversarial, as they pit schools against parents (Burke, 2013), as seen with Ms.

Yellow. This may lead to contentious sentiments between both parties, but can be an approach to increase the probability that parents requests are taken seriously.

Procedures manuals used in this study, came from California, Southern California and Washington, D.C. When applicable, manuals were used from a parents' specific school district. The manuals were used as a reference for parents when asked about their interactions with the manual. This was done because parents knew what the document was when they saw it, but not always by name. Parents were offered an opportunity to glance through the manual if they needed it for reference during the interview.

Readability. Using software on Microsoft Word, readability statistics were collected on each document. The readability tool indicated that each manual was written well above an 11th grade reading level. Table 10 illustrates key readability features identified for the manuals. Although readability is most commonly defined as the ease of reading and understanding of a piece of writing (Lo, 2014), I defined readability as all of the interactions that affect the successful use of the material, including the ability to understand the imparted information, read the information at an optimal speed, and find the information of interest (Dale & Chall, 1948), because the definition provided a more comprehensive understanding around *why* the writing in the manuals was meaningless for parents in this study. There are significant challenges if a document is written at or above a tenth-grade reading level (Lo, 2014; Pizur-Barekow et al., 2010; Roit & Pfol, 1984); simply put, when written as this level, the parent would need to have achieved a tenth-grade reading level to comprehend the document. However, for many parents of low SES communities, their actual reading level may be much lower than one would assume based

on degree attainment (Fujiura & Yamaki, 2000). Further, for at least one participant of this study, the parent had completed school through tenth grade.

Table 10

Word, Sentence and Readability Statistics

State	Pages	Words	Sentences	Flesch - Kincaid Grade Level
California	14	5,119	173	12.4
Southern California	16	8,343	229	14.3
Dist. Of Columbia	41	16,619	343	16.3

Factors inhibiting the readability of the manuals included legal jargon, complex sentences and passive sentence structures. Such features made understanding something as simple as a parent changing their mind about services more difficult to understand. This became a key point for Ms. Yellow when she did not want her son to be in a certain classroom but did not want to terminate special education services. She was told that she would have to sign a form terminating her son's services in order not to be placed into the classroom. Ms. Yellow signed, not realizing that she had terminated all services and ultimately exited her son from special education services. When she asked why her son was not receiving his speech services, she was informed that she had previously terminated her son's special education services. Her son had to be reevaluated to be readmitted into special education. Had the manual been written accessibly for the parent,

she could have understood that when the parent disagreed with the placement of her child, she had a right to ask for mediation, then due process. Furthermore, California law requires the student to "stay put" in the current program until the dispute is resolved (California Department of Education, 2019). This level of confusion could have possibly been avoided had the manual been clearer for the parent. Examples from each manual explaining parental revocation of consent are below.

California Procedures Manual (California Department of Education, 2019):

> *"When may I revoke consent?*
> *If at any time subsequent to the initial provision of special education and related services, the parent of a child revokes consent in writing for the continued provision of special education and related services, the public agency:*
> - *May not use the procedures in subpart E of Part 300 34 CFR (including the mediation procedures under 34 CFR Section 300.506 or the due process procedures under 34 CFR Sections 300.507 through 300.516) in order to obtain agreement or a ruling that the services may be provided to the child"*

Southern California Procedures Manual (XX Southern California Unified School District, 2017)

> *"If the parent revokes consent in writing for his/her child's receipt of special education services after the child is initially provided special education and related services, the school district or charter school is not required to amend the child's education records to remove any references to the child's receipt of special education and related services. This provision applies when a parent refuses all special education services. If a parent disagrees with some services, but not all, the issues need to be resolved through the Due Process procedure."*

Washington, D.C. Procedures Manual (OSSE, 2018)

> *" PARENTAL CONSENT - 34 CFR §§300.9 and 300.300; 5E DCMR §§3026.1 and 3005.2(b)*
> *If you wish to revoke (cancel) your consent after your child has begun receiving special education and related services, you must do so in writing. Your withdrawal of consent does not negate (undo) an action that has occurred after you gave your consent but before you withdrew it. In addition, the LEA is not required to amend (change) your child's education records to remove any references that your child received special education and related services after your withdrawal of consent."*

The complex lexicon, legal jargon, and overall vernacular make the explanation of parental consent confusing for a less educated parent. Even if the parent had understood the manual's explanation, it does not guarantee they would have understood how the rules applied to their particular cases.

Improving Procedural Safeguards

Given parent's lack of usage of the parents' manuals, each parent was asked for recommendations to improve its contents to make it more user friendly. Reasons why they did not use the manual included lack of time, layout of the manual, and difficulty understanding its contents. Responses included putting the manual online, creating an app to access the manual by phone and turning it into an audio book.

Beyond textual characteristics that hindered reading of the manuals, parents stated a lack of time to read the manual. Given their competing priorities of multiple children, high needs children and/or multiple jobs, time was a commodity that most did not have. Accordingly, parents needed something that would be easily accessible to quickly answer their questions. The disadvantage I observed most frequently related to a lack of understanding about procedural safeguards was parents' inability to apply the law to their questions. For example, Ms. Orange's dispute with the school not getting her daughter on the bus could be argued as a denial of FAPE. Her daughter attends a non-neighborhood school to attend a special program. If the student will not ride the bus because the bus attendants keep changing, the parent has an argument to have an aide ride the bus with her daughter to and from school to ensure she continues to receive FAPE. At a minimum Ms. Orange had a reasonable chance to argue that the school provide a classroom aide to walk her daughter to the bus and help her onto the bus at dismissal. However, currently

the school has left the responsibility to the child to put herself on the bus at dismissal. Neither the teacher nor the classroom aide walks the children to the bus when school is dismissed. Had Ms. Orange understood the law, she may have been able to argue her daughter's needs to the school. Instead, she argued that they should do "something different" and not call her because it impacts her ability to work, a strategy that is proving ineffective, as her daughter still does not get on the bus and Ms. Orange is called almost daily to pick her up.

One of the suggested improvements from the parents that included a technology solution (i.e. app, online publication), while useful, does bring to question how parents will navigate an electronic version of the manual differently from a handheld book. If school systems do not understand how parents interface with digital platforms, placing the manual online will be no different than sending parents an emailed version of the manual. More needs to be understood about how parents utilize search engines, swiping versus tapping/clicking to access information and how they utilize hyperlinks when searching for answers. Additional research is also needed in understanding how parents from low SES communities apply what is in the manual to their needs.

Finding Answers

When attempting to find answers to their questions, parents repeatedly stressed the difficulty of finding information. Some noted that it felt as though the information was hidden. This response was predominantly from families living in Southern California.

In Washington, D.C. parents relied on the Special Education Coordinators in their child's building as a primary contact. Secondary resources included people who knew the

special education process, such as former administrators, social workers, and former teachers. One parent also relied on community-based organizations.

In Southern California, parents relied on community-based organizations, Google, Siri, and relatives. Due to the lack of resources in the school buildings, or because of the strained relationships with staff in school buildings, families in Southern California relied heavily on resources outside of the school. Each of the families in Southern California listed a community organization they accessed for reviewing their child's IEP or obtaining advice on questions about services for their child. These families also mentioned bringing a family member, usually a maternal grandparent, to the meetings, either as a surrogate if they were unable to attend or as additional support. Southern California parents mentioned the desire to bring someone from the community-based organizations to the meetings with them; however, based on parent reports, most organizations did not send representatives into the schools. They only provided advice to parents on questions they should ask while in the meeting. Ms. Yellow described the limitations to this approach when she said,

> *"If there's something that we're talking about and that's where I'm still frustrated, I can't help it, I'll forget about the other thing that I wanted. I went in there and I really wanted to talk about augmenting his speech issues and goals, but we got so much into the whole behavior thing, I forgot all about that…..Sometimes I feel like I miss things just because I'm so focused on something that I missed somewhere else."*

Having lived in both Washington, D.C and Southern California, it is noteworthy to mention that as a newcomer to the state of California, I found it difficult to find answers about special education at the school level. Simple questions to school staff members (i.e., general education teachers, school counselors, special education teachers), such as how to start a referral in their building, were met with blank stares, uncertainty

and inconsistent responses. Speaking to the principals painted a clearer picture of the referral process in a building; however, the answer was different in each building. At best, the process was that a parent made a request and a referral meeting was held. However, this was only heard at one school out of 15 this researcher contacted. More likely was a response about the intervention process in the building. The intervention process was different in each building. As a person with a background in special education, I was able to make some sense of how a referral occurred. However, it was difficult to get consistent responses from multiple people in the same building.

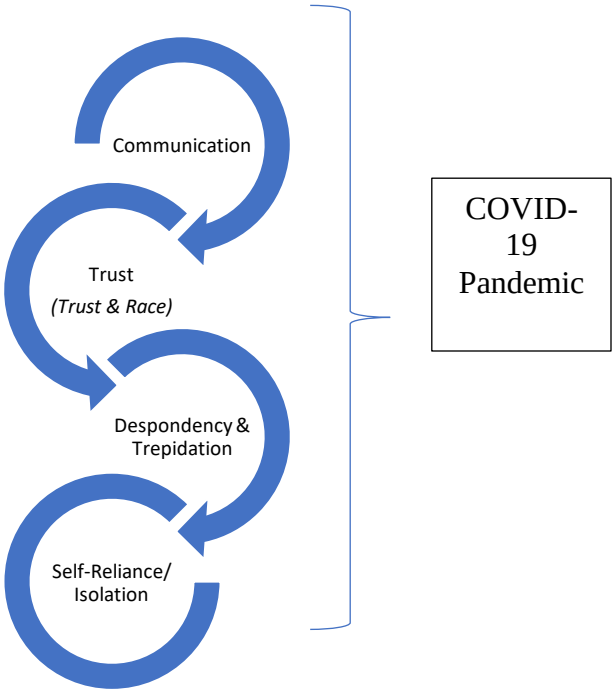
How It All Connects

Throughout the interview and data analysis phase, it became apparent that the essence of the parental participants' experiences contained similar tenets of communication, trust, trepidation, isolation and the COVID-19 pandemic. These tenets were not isolated individual concepts, but interconnected to one another to describe the comprehensive essence of the lived experience for parents from low SES communities making decisions about their child's special education needs. Figure 7 demonstrates how the concepts previously discussed of communication (either the medium or in how/what is said) led to a series of rippling outcomes that impacted a parent's ability to make decisions when navigating the special education system.

A breakdown in communication between education professionals and the parent impacted the parent's ability to trust the information shared with them about their child. Eroded trust in the educational system or the people in the system designed to support their children, elicited sentiments of despondency and trepidation. Despite these feelings, because each parent was resolute in supporting their child with disabilities to the best of

Figure 7

Connection Between Overarching Themes



their capability, they called upon self-reliance as the mechanism needed to ensure their child obtained what they needed for success. As such, the cumulative effect of each tenet of communication and trust, when broken, led to feelings of despondency, trepidation, and self-reliance that left parents feeling isolated in their experience of parenting their child with special needs. In this matrix of cause and effect, the essential lived experience of the parent could be improved from the start, through the improvement of communication at a minimum, and intervention in all superordinate themes to improve this lived experience for parents from low SES communities. These experiences were intensified in the context of the COVID-19 pandemic. If a parent had a positive experience, that experience continued. However, if the experience was negative, it was intensified given the financial loss/job uncertainty experienced by each participant during the pandemic and nationwide shutdown.

Theoretical Framework

This study was conducted through the lens of the Heuristics and Biases Framework (Kahneman & Tversky, 1973), with an emphasis on the use of availability and category-based judgement heuristics. To address the question of how judgement and behavior is shaped through basic psychological processes, this framework was used to understand how parents from low SES communities both received and processed information to make decisions under circumstances of uncertainty, especially in the face of ambiguous, complicated, and/or incomplete information (Chaudry et al., 2010; Thaler & Sunstein, 2008; Tversky & Kahneman, 1974). The use of heuristics was theorized to be a useful tool for parents from low SES communities to simplify complex information presented to them while navigating the special education process for their children with special needs.

"Category-based judgements", where parents rely on knowledge of a particular category or class of information to arrive at a conclusion about a particular case (Kahneman & Tversky, 1973), observed in this study suggested that parents from low SES communities lack a full understanding of how their actions or decisions may impact their ability to be successful advocates for their child with special needs. As a whole, the participants in this study emphasized a need for mutually respectful and supportive relationships with education professionals, but responded to disagreements with actions that were detrimental to forming such professional relationships. Actions such as tape-recording staff without their knowledge, filing due process complaints, not attending meetings, and appearing aggressive or confrontational in their interactions were all actions that created barriers to generating positive working relationships.

"Category-based judgements" that impacted parents' decision-making related to how parents interpreted the results of their actions. In scenarios where parents made phone calls to complain about a desired resolution to a problem, they concluded that because the person they complained about treated them differently in their next interactions that their individual actions had an impact, despite not solving the original problem. For the parents in this study, the role of the category-based heuristic suggested that under conditions of high accountability expectations of the parent (in the outcomes for their children), combined with inconsistent education staff assumptions (what staff believe their child can do versus what the parent believes), these parents from low SES communities applied the heuristic of "category- based judgements" to rationalize their conclusions when they did not agree with the end result. As such, issues of race, how someone makes them feel, or what someone thinks their child can do become the construal used for disagreeing with the education professionals.

"Availability heuristics", making decisions based on available information, were observed in how participants made decisions in IEP meetings. For many of the parents, although they did not identify concerns about the IEP meeting itself, despite often noting that they felt "heard" by the staff, parents did not connect the concerns they had about their child's entire educational experience as a part of the IEP process. In these instances, the parents in this study tended to weigh their decisions toward the most recent information presented at the meeting, and made decisions based on the information presented at the meeting. This decision-making process allowed parents to make an immediate decision about the child's education; however, the decisions they made did not

align with their long term goals for their children. This left parents in the study feeling overly distressed about the long-term success of their children.

Suggestions to Enhance the Conceptual Framework

Based on my findings, I would suggest that it is important to also consider the role of the *affect heuristic* when parents from low SES communities make decisions about their child's special education needs. An *affect heuristic* is a mental shortcut that is used when individuals make decisions that are heavily influenced by their current emotions (Finucane et al., 2000). In such an instance, the way an individual feels (their affect) toward a particular stimulus influences the decisions an individual makes. This heuristic was observed with parents in this study throughout, as parents, decisions were heavily influenced by how they felt about the person giving the information or making the decisions. Whether the decision was influenced by race that elicited an emotion or gradients of trust that elicited an emotion, each resulted in a final emotion that impacted the parent's final decision of whether to accept the information given to them. Including this heuristic would strengthen the conceptual framing for the study.

Although my original theoretical framework was supported by the results of this study, an additional framework could be applied for future studies, such as the DisCrit framework (Annamma et al., 2013) to better understand the role of race and its impact on trust among parents from low SES communities that have a child with a disability. Tenet's from DisCrit would firmly explore the ways in which race and ability are both socially constructed, yet still interdependent (Annamma et al., 2013). Through an analysis of structural power and racism through a historical, social and economic lens of limited access to educational equality to African American students with a disability,

including DisCrit in the conceptual grounding for future studies may expand knowledge and understanding of the intersectionality of race, disability, socioeconomics and trust among education professionals. It may also reveal if the perceptions identified in this study among African American parents from low SES communities crosses socioeconomic lines among African American parents with a child with a disability.

Recommendations

When navigating the special education process, this study identified the following concerns for parents:

a) Educator respect for parents and children
b) Improving access to information and assistance in identifying community support services
c) Improving cultural understanding by school personnel
d) Improving commitments to students that are identified with disabilities

By addressing these concerns, parents may experience fewer institutional barriers (i.e., meeting times, paperwork) and psychological barriers (i.e., mistrust, powerlessness) that inhibit their ability to navigate the special education process more successfully.

A review of findings situated in the heuristics and biases conceptual framework for this study led to recommendations that should be considered based on the experiences of parents from low SES communities navigating the special education process. These concerns can be addressed in the areas of policy, practice and research. Table 11 summarizes the recommendations based on the findings from the study.

Table 11

Summary of Recommendations in Practice, Policy, and Research

Category	Recommendations
Practice	1. Professional Development – Both parents and education professionals require skills and knowledge about communication, collaborative decision making, and cultural competence. Trainings may be provided through pre-services and throughout the school year through professional developments and parent workshops. 2. Special Education Liaisons - Identify one person in each building that parents can go to for special education information that is not connected to disciplinary or academic decisions.
Policy	3. Parents Procedures manuals readability should be reviewed to allow equitable access for all parents regardless of educational attainment. More specification in IDEA in how to define "accessible" is needed to determine readability guidelines. 4. Manuals should be presented to parents in various formats, such as digital, audio version and printed to allow parents to access information in a modality that is best for them. 5. More comprehensive surveys should be developed for each school system to detect the quality of parental participation rather than just monitoring quantity of parental participation.
Research	6. More research is needed regarding the interaction between parents and community-based resources and how parents use these resources to make informed decisions.

	7. More research is needed on the role of race for African American parents of a child with a disability from low-income communities when considering credibility of information from others of a different race 8. More research is needed in the examining the role of having a child with a visible/medical disability versus an invisible/non-medical disability has on a parent's ability to describe how the disability impacts their child.

Recommendation 1 – Professional Development to Grow Cultural Cognizance Across Socio-Economic Variances

Based on experiences from parents, feedback provided by educational professionals was at times dismissive and non-conducive to fostering strong home-school partnerships. Valle (2002) as well as Conner and Cavendish (2017) urge education professionals to view parents beyond their policies and procedures and instead view parents as individuals already navigating challenging personal and familial situations. Professional development should focus on increasing education professionals' knowledge about families with diverse backgrounds. Professional developments should go further than cultivating an understanding of different cultures by emphasizing stratagems to build alliances among those of different socio-economic and cultural groups. Recognizing that education professionals are charged with responding to the diverse needs of their parent body, who may differ significantly from themselves in terms of their own social class, race, ethnicity and education, is an indication that more professional development needs to be implemented to enhance cultural cognizance.

Recommendation 2 – Special Education Liaisons

Based on the responses from parents in the study it became evident that the ability to find answers to questions and to navigate special education services correlated with the ease of finding answers to questions. Each parent in DC had a designated person in their child's school buildings whose sole responsibility was to provide information for parents and to ensure special education compliance. These staff members were not involved in the child's day-to-day education or disciplinary decisions. Although they were a part of the school administration and a part of the child's IEP team, they were not involved in potentially emotionally-laden decisions, such as failing or suspending a child. Conversely, parents in Southern California had to rely on someone in their child's school building that did hold such a role (i.e., teacher or principal). When trust is mitigated by emotionality, parents experienced more difficulty gaining answers to their questions. Given this dichotomy, schools should consider incorporating non-disciplinary staff members who can aide parents in finding answers to their questions as they make decisions for their child's special education needs.

Recommendation 3 – Improving Readability

IDEA requires schools to safeguard parental involvement so that it is both meaningful and confirms a parent's understanding of their procedural rights and the proceedings. Section 300.300 of IDEA states that parents must be fully informed about, understand and agree, in writing, to a specific activity related to the provision of special education services for their child; yet how does a parent do this if they are unable to access the information in the written material such as the safeguards manual? Past research has indicated that a fifth-grade reading level was appropriate for school-developed materials for parents, including those living at or below the poverty level, due

to many parents reading up to six grade levels lower than their highest grade of completed formal education (Lo, 2014; Pizur-Barekow et al., 2010; Roit & Pfol, 1984). Despite these recommendations, the manuals used in this study were all written above an 11th grade reading level. Greater attention needs to be given to the development of not only all written materials disseminated to parents, but particularly to the Parents Rights and Procedures Manuals, to ensure that not only the letter of the law of IDEA is met, but also its intent. Future manuals should take into consideration not only sentence lengths, word counts and syllable counts, but also layout, design format and access.

Recommendation 4 – Material Presentation

Additional research is warranted in the areas of how parents from low SES communities interface with technology to find information. Many of the participants suggested putting the manual online as one solution to encourage using the manual more. If the procedures manual is placed online, more research is needed on the best methods to increase interaction with the manual. Otherwise, the manual can be sent to the parent via email in its same format, although I predict that such a method will prove to be as ineffective as giving out the physical handbook.

Additional variations of the manual could include audio versions, apps for the phone, and video with close captioning.

Recommendation 5 – Surveys to Determine Quality of Parent Participation

The responsibility of education professionals to evaluate the knowledge acquired by parents from written materials to ensure parents are making informed decisions and providing "informed consent" should be added as a part of routine practice. States currently monitor parent participation but do not monitor the *quality* of the participation.

Surveys that capture the experience of the parent should be included as a part of the special education process. Schools should also take on more responsibility to measure their ability to educate parents about the ramifications of their decisions made throughout the special education process as well as the process itself. Such understandings on the part of the parent would encourage more authentic parent participation.

Recommendation 6 - Research on How Parents Use Community Resources

More research is needed to understand how resources outside of the school assist parents in their educational decision making about their child's special education needs. While there is research about parents' use of support groups, there is a gap in the research on how parents utilize external resources to improve their decision-making. In this study, parents who did not have an immediate resource in the school went to different community-based organizations for answers to their questions about their child's special education. Questions varied from inquiring if the goals were appropriate to questions about placement and diagnosis. Connecting these resources to parents and schools may provide additional support to improve experiences for parents and their children with special needs.

Recommendation 7 – Research the role of race for African American parents of a child with a disability from low income communities when considering credibility of information from others of a different race

More research is needed on how race culture effects African American parental attitudes towards those not of the same race in educational settings. This question could be further expounded to all races to determine if race itself effects trust of individuals not of the same race. In this study, African American parents described a distrust of

judgements/recommendations made about their child based on the race of the person providing the information. Given the notion that there is a bidirectional relationship between parental attitudes and behaviors regarding their child's education, it is necessary to ask if African American parents deem culture a liability in their child's education, regardless of disability status.

Recommendation 8 – Impact of Visible/Medical Disability Versus Invisible/Non-Medical Disability On Parent Ability to Describe How the Disability Impacts Their Child

Throughout this study, I observed that parents of children with a medical disability were better able to describe how the disability impacted their child's learning. More research is warranted in this area to determine if this is because these disabilities are visible disabilities and medical, and thus more "straightforward" in terms of pinpointing specific areas of need (i.e., loss of hearing, chromosome abnormalities, muscular impairment). Do doctor's do a more thorough job of explaining a child's disability to the parent that allows them to understand the depth and complexity of a child's disability in multiple settings? Do the multidisciplinary teams involved in identifying invisible disabilities at school experience challenges in thoroughly explaining the impacts of these disabilities (e.g., developmental delays, impulsivity, reading disorders) for children in multiple settings? While improving parent education at the school level would likely improve parent's ability to advocate successfully for their child's special education needs, it is important to understand why parents of children with medical disabilities were better able to more thoroughly describe their child's disability and its implications than were parents of children without medical disabilities.

Limitations

Limitations to this study include the exclusion of the experience of non-English speaking parents. As multiple translators were unavailable to support non-English speaking parents, their experience navigating special education was not explored. Additional limitations were that only parents from an urban environment were included. The lived experience of low-income parents in suburban and rural areas navigating the special education process may be different from their urban counterparts. Additionally, the study is limited in its generalizability due to the small sample size.

While the findings from this study may contribute to the limited body of research on this topic and may assist in the development of future staff professional developments, written policies and parent/school interactions, these findings are specific to this sample of parents and are not widely generalizable. This study was further limited by the nature of qualitative research in which the data collected represented the perceptions and beliefs of only the participants, and cannot be generalized beyond the scope of the study. As this study only included the perspective of the parent, it provides a one-sided view of the experience. Although the perceptions of the lived experience by the parent is valuable in its knowledge, it does not reveal the same experience as shard by the education professionals involved.

Finally, the readability tools used to analyze the Procedures Manuals were an additional limitation. Readability tools themselves also have limitations as they are unable to measure the context, prior knowledge, interest level, difficulty of concepts, or coherence of a text.

Conclusion

Similar to work by Valle (2002), Audrey Trainor (2010), and Conner and Cavendish (2017), the findings of this study indicated that the experiences shared by parents from low SES communities navigating the special education process reflected how difficult negotiating a school system can be for parents. Despite differences in race, ethnicity, language, location and child's disability, parents shared common sentiments about their decision-making experiences while advocating for their child's needs. Based on these shared experiences it is possible that cultural differences that arise from the differences in economic class may be harder to overcome in the creation of trusting relationships.

To improve the experience of parents from low SES communities navigating special education for their child with special needs, academic professionals need to view parents beyond their policies and procedures as people who are attempting to navigate their own challenging personal and familial circumstances. Increased empathy and understanding of parents' lived experiences by academic professionals may foster environments that are more conducive to parental well-being and improved educational outcomes for their children. When school professionals cultivate themselves as an ally rather than an adversary to parents, it will be a step in the direction of increasing communication and decreasing power differentials between staff and parents.

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Appendix A

THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

INFORMED CONSENT

The Lived Experience of Parents From Low SES Communities While Navigating The Special Education Process

IRB # NCR191449

Principal Investigator: Monica Arce Whitlock, MSA, M.Ed

Introduction

You are be asked to participate in a research study conducted by Monica Arce Whitlock, a doctoral student at The George Washington University (GWU). This study will be used as a part of the requirements for her degree. You are being asked to participate in this study because you are a parent or guardian of a child with an IEP. Taking part in this research is completely voluntary and even if you decide you want to participate today and later decide you do not want to participate, you can withdraw at any time. At the end of your interview you will receive a $10.00 grocery gift card for your participation.

Purpose

The reason for this study is to answer the following questions about parents from low income communities and their child with an IEP. This study wants to know how these parents:

1) understand their child's disability
2) experience going through the different parts of the special education process
3) understand their legal rights and responsibilities in the special education process
4) find information and resources for your child with an IEP

Procedures

This study will include interviews with Monica Arce Whitlock. The interviews will last about an hour to an hour and a half. Interviews can be broken into more than one if time is a concern. If you agree to participate, you:

- Will be asked to participate in an interview with Monica Arce Whitlock to learn more about your experiences as a parent of a child with an IEP
- Will be asked to share information about your income, child's disability and your experiences making decisions for your child

- Allow researchers to record the interview for accurate reflection on your input records
- Will receive a $10.00 gift card to a local grocery store for your participation

Risks and Confidentiality

The interview will be audio record so that they can be transcribed for the study. I will destroy the audio recordings as soon as the transcriptions are complete. We will store transcriptions digitally on a password-protected study-dedicated computer. All files will be in PDF form and have an access Password that is known only by myself.

The study has the following risks: It is possible that you may feel some emotional stress/discomfort when you answer the interview questions. You may feel uncomfortable saying the names of your child's school, teacher, school administrator or saying any other identifiable information. There is a very small chance that someone not on the research team may somehow connect your name with the information collected. However, the following steps are being taken to reduce this risk:

- No identifiable information will be included in written documents.
- All transcripts and data will be password protected and saved on a password protected computer.
- The records of this study will be kept private.
- Only trained research team members will have access to it.
- In any published articles or presentations, I will not include any information that will make it possible to identify you as a participant.
- Your records for the study may be reviewed by the Dissertation Committee for Monica Arce Whitlock at the George Washington University.

Benefits

Your participation in this research may not help you directly. However, your participation in this study may help parents, teachers and school administrators. The benefits to science and humankind that might result from this study are the following: your responses and my ability to gather data about how you experience going through the special education process may help us and future researchers develop appropriate interventions and supports to increase parent decision making in schools. This may be linked to improved parent-school interactions, improved parent knowledge about the special education process and improved outcomes for parents during IEP meetings. It is important for us to understand this because it will allow us to understand how to best share information with parents that will support them in making informed decisions about their child's special education needs.

Who should I ask if I have any questions?

If you have any questions about this study, you can call Monica Arce Whitlock at (202) 255-2911. The Office of Human Research of George Washington University, at

telephone number (202) 994-2715, can provide further information about your rights as a research participant. You may also contact the Institutional Review Board (IRB) office if you have questions, concerns, or complaints about this research, or wish to talk to someone independent of the research at ohrirb@gwu.edu.

Documentation of Consent

If you agree to take part in this study, please sign and date below.

☐ I consent to participate in this study.

☐ I do not consent to participate in this study.

Name (please print) _____

Name (signature) _____

Date _____

Appendix B

Participants Needed

Do you have a child with an IEP? Do you have ideas on how to make special education better? Join a study for parents of children with disabilities.

To qualify for this study:

1. **You must be the parent or guardian of a child receiving special education services.**
2. **You must qualify for the Free and Reduced Lunch program at your child's school.**
3. **Be fluent in English.**

Participants will receive a $10.00 gift card to a local grocery store for participating.

Interested: Call Monica Arce at (202) 255-2911

Email: arcem@gwu.edu

Appendix C

Interview Questions

Introduction:

Thank you so much for joining me today. As you know I am a graduate student that is working on my doctorate. Today's interview is a part of my study for my degree. My goal is to learn more about what parents of special needs children in a lower income bracket know about special education and if you have enough information to make informed decisions about your child's services. Is it okay if I record today's interview?

Background Information:

I. What is your name?

II. What is your occupation:

III. What income group do you belong to?

   a. Less than $10,00 per year

   b. $10,000 -$12,000 per year

   c. $12,001 - $15,000 per year

   d. $15,001 - $18,000 per year

   e. $18,001 - $20,000 per year

   f. $20,001 - $22,000 per year

   g. $22,001 - $25,000 per year

   h. $25,001 - $28,000 per year

   i. $28,001 - $30,000 per year

   j. More than $30,000 per year

IV. What is your highest level of education?

V. How many people do you support in your home?

VI. How many children do you have that are receiving special education services?

VII. How long has your child(ren) been receiving special education services?

VIII. What is your child(s) disability?

IX. Can you describe what a _____ is? (the blank will be filled in with their child's disability

X. How does this impact their learning?

XI. Do you feel that this disability describes your child(ren) correctly?

a. Why/why not

RQ1: How do parents of low SES communities experience their child's disability?

1. Can you describe what a _____ is? (the blank will be filled in with their child's disability
2. How does this impact their learning?
3. Do you feel that this disability describes your child (ren) correctly?
4. How do you feel about your child's academic future in school?

RQ 2: What is the essence of the lived experiences of parents who live in poverty when navigating the process of special education eligibility, identification, and service planning during interactions with school personnel?

1. Describe how you feel as a parent of a child with a disability when sitting in a school meeting.
2. Have you ever had a time when you disagreed with the special education team? What happened?
   a) Where you satisfied with the outcome?

3. Have you ever had a time when you did not speak up when you disagreed with something?
    a) Potential follow up: what kept you from speaking up

RQ3. How do parents from low SES communities interpret their rights and responsibilities in the educational process?

1. What can you tell me about this document (referring to the procedures manual)
2. Have you ever used it to find an answer to a question? What if yes. Why not if no.
3. When you are sitting in meetings, what do you wish you knew more about?
    a. Potential follow up: Is there anything about special education law you wish you knew more about?

RQ4. How do parents of students with disabilities from low SES communities describe their experiences in finding information and resources for their child with special education needs?

1. If you disagreed with something in your child's IEP or evaluation, what would you do?
2. How would you describe the experience of getting answers for your questions about your child when you aren't sure about something?

Is there anything else you would like to share about your experiences as a parent of a child with a disability?

Do you have any questions for me?

Thank you for taking the time to talk with me today. The feedback you've given has been extremely helpful.