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Lived Experiences of Caregivers Navigating the Individuals with Disabilities Education Act For Their Disabled Children

Natasha Weber Holmes
Walden University

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Walden University

College of Education and Human Sciences

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Natasha Weber Holmes

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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Walden University
2026

Abstract

Lived Experiences of Caregivers Navigating the Individuals with Disabilities Education

Act For Their Disabled Children

by

Natasha Weber Holmes

MA, Walden University, 2022

BS, American Public University, 2019

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Developmental Psychology

Walden University

August 2026

Abstract

The Individuals with Disabilities Education Act (IDEA) was designed to guarantee equitable access to special education services for children with disabilities. Yet, disparities persist in how caregivers navigate protections. They often face barriers related to limited legal knowledge, inconsistent school support, and systemic inequities, leaving many unable to fully advocate for their children. The purpose of this interpretative phenomenological analysis study was to explore lived experiences of caregivers as they engaged with the IDEA to secure services for their children with disabilities. Guided by the legal consciousness and empowerment theories, the study involved examining how caregivers interpret and act upon their legal rights and how their sense of empowerment influenced their advocacy behaviors. The central research question is: What are lived experiences of caregivers navigating the IDEA for their children with disabilities? Participants were six caregivers who were recruited through community organizations and social networks. Data were collected through semi-structured interviews. Five themes emerged: navigating the IDEA without guidance, power of self-advocacy and knowledge, barriers within school systems, role of external support networks, and preparing children for independence. Findings revealed while many caregivers initially lacked clarity about their legal rights, they became more confident advocates over time when supported with networks and access to legal information. This study contributes to positive social change by addressing advocacy challenges caregivers face and emphasizing the need for accessible legal literacy and equitable school-based support systems that empower families of children with disabilities.

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Dedication

This dissertation is dedicated to my incredible support system. To my husband, who has encouraged me every step of the way, picked up the slack when I needed it most, and always cheered the loudest, your unwavering belief in me has been my anchor. To my beautiful children, Mykhael (Michael) and Mayson, one of my greatest “whys,” I hope this work shows you that you can achieve anything you set your hearts and minds to. To my mom, whose constant love, encouragement, and pride in “her baby becoming a doctor” has fueled me more than she knows. And to my best friend, Arielle, who inspired me to begin this PhD journey alongside her and has been my confidant, motivator, and sounding board through every obstacle, I could not have done this without you. I appreciate you more than you know, and it is going to be amazing to walk across the stage and get our degrees together!

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Chapter 1: Introduction to the Study

Across the United States, millions of children with disabilities receive educational services via the Individuals with Disabilities Education Act (IDEA), which mandates access to a free and appropriate public education (FAPE). Despite this legal framework, many caregivers continue to face persistent challenges involving understanding and exercising their rights. Navigating the IDEA involves interpreting complex procedural safeguards, advocating during individualized education program (IEP) meetings, and initiating due process hearings. While some caregivers are highly informed and empowered, those from marginalized backgrounds struggle with limited knowledge of their legal rights, resulting in inconsistent access to critical services and supports (Burke et al., 2022; Mann & Gilmore, 2023; Rosetti et al., 2021). These disparities highlight the importance of examining caregivers' lived experiences with the IDEA, as their ability to advocate effectively is often a decisive factor in terms of whether children receive equitable educational opportunities (Harry & Ocasio-Stoutenburg, 2021; Szlamka et al., 2022).

This study was needed because prior research highlighted barriers such as systemic delays, fragmented service delivery, and the emotional toll of advocacy. However, there is insufficient information regarding how caregivers' legal knowledge and sense of empowerment shape their advocacy behaviors. Without these insights, efforts to improve IDEA implementation risk overlooking the foundational role of legal consciousness in terms of enabling or constraining advocacy. By centering caregivers'

voices, I addressed a critical gap in literature and provided a deeper understanding of how families navigate the IDEA in real-world contexts.

Potential positive social implications of this study extend to families, schools, and policymakers. Findings may inform design of caregiver training modules, targeted outreach programs, and policy reforms that move beyond general self-efficacy, building to emphasize legal literacy and empowerment. Strengthening caregivers' understanding of the IDEA can support more equitable access to services, reduce disparities, and promote positive developmental outcomes for children with disabilities (Burke et al., 2022; Szlamka et al., 2022). This chapter includes the background of the study, research problem, purpose of the study, research question, theoretical framework, and nature of the study. The chapter concludes with a discussion of the study's significance and summary.

Background

Recent empirical work underscores the complex nature of caregivers' experiences as they engage with IDEA legal and educational frameworks. Burke et al. (2022) demonstrated that a structured legislative advocacy program significantly enhanced parents' knowledge of special education law and their self-efficacy in terms of policy engagement, leading to more confident and effective advocacy behaviors. Additionally, Harry and Ocasio-Stoutenburg (2021) stated although legal frameworks can empower caregivers to secure essential services, the advocacy process often entails considerable emotional strain and systemic resistance, highlighting the dual role of empowerment and burden in terms of caregivers' legal consciousness.

Beyond individual advocacy efforts, systemic and relational factors further shape caregivers' lived experiences involving the IDEA. Sapiets et al. (2023) identified bureaucratic delays, fragmented service delivery, and socioeconomic and geographic disadvantages as critical barriers to accessing early intervention supports which are precursors to IDEA-mandated services. Streamlined referral processes and proactive provider communication serve as important factors for success. Mann and Gilmore (2023) found misalignments involving expectations, cultural and language challenges, and time constraints can undermine parent-school partnerships in inclusive settings, thereby hindering collaborative efforts to effectively implement IDEA provisions. Advocacy training, emotional and practical burdens, and systemic obstacles define complexities caregivers face while navigating the IDEA for their disabled children.

Burke et al. (2022) demonstrated structured legislative advocacy programs can bolster parents' legal knowledge and self-efficacy, leading to more confident engagement with policy processes and improved advocacy outcomes. Rossetti et al. (2021) stated parents perceive implicit expectations to advocate for their children's educational needs, and intensity and impact vary significantly across socioeconomic and cultural lines. Szlamka et al. (2022) demonstrated when families feel empowered, they can more effectively influence the design and delivery of services; however, disparities in terms of empowerment continue to perpetuate inequities involving service access. Together, these studies demonstrate the complex interplay between parental beliefs, institutional invitations, and systemic constraints that shape advocacy outcomes in terms of the IDEA.

Despite these valuable contributions, few studies directly investigate caregivers' awareness of their legal rights according to the IDEA and how legal consciousness influences advocacy behaviors and children's actual access to services. While advocacy training programs have addressed general self-efficacy and law-related knowledge, they are insufficient in terms of examining caregivers' understanding of procedural safeguards (e.g., notice and consent requirements) or entitlement provisions (e.g., free and appropriate public education). Likewise, research on systemic barriers and family empowerment rarely involves gaps in legal knowledge and lived experiences in ARD/IEP meetings or the use of due-process mechanisms. As a result, there is a lack of information regarding how limited legal awareness constrains caregivers' advocacy efficacy and in turn affects developmental outcomes for disabled children, a gap I sought to address.

A large body of research underscores the importance of parental advocacy in terms of securing educational rights for children with disabilities; however, few studies investigate the foundational role of caregivers' legal consciousness, specifically their detailed understanding of IDEA procedural safeguards and entitlement provisions. While structured advocacy programs have demonstrated improvements in terms of parents' self-efficacy and law-related knowledge, as well as emotional and practical burdens of advocacy, there is insufficient information regarding how specific legal knowledge gaps translate into missed opportunities during ARD/IEP meetings or underuse of due process mechanisms. Moreover, although disparities involving empowerment and systemic access have been linked with socioeconomic and cultural factors, precise ways in which limited legal awareness compounds these inequities remain unexplored. Addressing this

gap is essential, as the legal consciousness theory suggests individual internalized perceptions of law directly affect their capacity to claim rights and navigate institutions.

By directly examining caregivers' awareness of IDEA rights and protections, I sought to advance both theory and practice. By doing so, I aim to inform training modules and targeted interventions that go beyond generic self-efficacy, emphasizing entitlement literacy and knowledge of specific procedural safeguards. The research provides policymakers and practitioners with actionable insights for reducing disparities involving special education access and strengthening support structures for caregivers. Ultimately, a better understanding of legal consciousness among parents will enable more equitable implementation of the IDEA, ensuring all children receive FAPE to which they are entitled by law.

Problem Statement

The specific research problem I addressed is caregivers of children with disabilities often demonstrate inconsistencies in terms of their understanding of rights, resources, and services their children are entitled to according to the IDEA, which can limit their ability to advocate effectively and secure appropriate services. Although the IDEA was designed to guarantee equitable access, disparities persist in terms of how protections are realized. Families with limited legal literacy or advocacy resources frequently encounter uneven access to IEPs and IDEA-mandated supports. Advocacy training and systemic reforms can strengthen parent engagement (Burke et al., 2022; Mann & Gilmore, 2023) and empowerment can enhance families' ability to influence service delivery (Szlanka et al., 2022). However, there is insufficient information

regarding differences involving caregivers' legal knowledge. As a result, little is known about how families with varying levels of legal consciousness and empowerment interpret and act on IDEA protections in practice.

Without these insights, interventions that are aimed at reducing equity gaps often overlook key factors that determine whether families can effectively access IDEA rights. Addressing this gap is essential for developing strategies that enhance both legal literacy and empowerment, ensuring all caregivers can advocate effectively and children can receive FAPE under federal law.

Purpose of the Study

The purpose of this qualitative study was to explore the lived experiences of caregivers navigating the IDEA for their children with disabilities. Guided by the legal consciousness and empowerment theories, I aimed to understand how caregivers interpret, make sense of, and act upon their legal rights via the framework of the IDEA. Specifically, I examine how varying levels of legal knowledge and empowerment shape advocacy behaviors and influence families' ability to secure IDEA protections. By addressing differences involving legal knowledge, I aim to provide nuanced insights regarding intersections of legal literacy, empowerment, and advocacy outcomes. Ultimately, findings will contribute to scholarship and practice by highlighting strategies that support equitable access to IDEA services for all families, regardless of their initial level of legal awareness.

Research Question

The research question that guided this study was: What are lived experiences of caregivers navigating the IDEA for their disabled children?

Theoretical Framework for the Study

This study is grounded in the legal consciousness and empowerment theories, which provide a comprehensive lens for examining how caregivers' understandings of IDEA shape their advocacy behaviors and influence children's access to services. Ewick and Silbey (1998) explained individuals construct meanings of the law via everyday experiences, perceiving them as enabling, constraining, or irrelevant. Whether caregivers frame the IDEA as a powerful tool for securing their children's rights or as another bureaucratic hurdle influences how they engage with procedural safeguards, such as evaluations, IEP meetings, and due process hearings. This theory highlighted the significance of everyday narratives in determining whether the law is used as a vehicle for advocacy or left unclaimed.

The empowerment theory complements this perspective by focusing on how individuals develop the capacity to act effectively within institutional systems. Conger and Kanungo (1988) described empowerment as a process that involves integrating meaningful participation in decision making, developing critical awareness of resources and structures, and translating understanding into concrete actions. Zimmerman (1995) defined empowerment as a multidimensional construct, encompassing intrapersonal (self-efficacy and perceived control), interactional (critical knowledge of systems and resources), and behavioral (advocacy actions) dimensions. When applied to the IDEA,

the empowerment theory helps explain why some caregivers confidently leverage legal knowledge to secure services, while others are constrained by uncertainty or lack of information. Foster-Fishman et al. (1998) stated more knowledge regarding self-efficacy and systems will enhance individual abilities to advocate effectively.

I integrated these two theories to address how caregivers interpret legal consciousness and translate that interpretation into empowerment. Caregivers who perceive the IDEA as a tool for agency are expected to demonstrate intrapersonal empowerment in terms of self-efficacy during advocacy. Interactional empowerment and critical knowledge of IDEA procedural safeguards mediates the relationship between legal understanding and behavioral outcomes, including requesting evaluations, ensuring compliance during IEP meetings, or initiating due process hearings. Legal consciousness and empowerment theories were a dual framework for analyzing caregivers' lived experiences and examining how they interpret and engage with the law. IPA privileges meaning-making in terms of lived experiences. By linking narrative interpretations of the IDEA with dimensions of empowerment, the study made both theoretical and practical contributions, highlighting mechanisms that enable or inhibit equitable access to IDEA protections.

I employed a phenomenological and story-driven approach that centered caregivers' voices. Through in-depth interviews, parents were invited to share their understanding of their legal rights, challenges they faced, and creative ways they secured educational support their children needed.

Integration of these theories helped fill a critical gap in literature by linking caregivers' specific legal knowledge or lack thereof with their advocacy efficacy. Insights will inform design of targeted interventions, such as educational workshops or resource guides, that build caregivers' self-efficacy and enhance their knowledge via the IDEA. Ultimately, I aimed to support a more equitable implementation of the IDEA and promote positive developmental outcomes for children with disabilities.

Nature of the Study

IPA was used to address caregivers' stories. By addressing these firsthand narratives, I uncovered deeper meanings they attach to their legal and educational encounters, which are insights that a survey or chart could not reveal. The key phenomenon under investigation is caregivers' subjective experience involving understanding and using IDEA procedural safeguards and entitlement provisions, and how these experiences support or hinder their advocacy and children's development. I am especially interested in how caregivers' limited legal knowledge creates information gaps, which in turn lead to emotional tolls and systemic roadblocks. By examining these real-world challenges and strategies caregivers employed, I sought to understand how varying levels of legal knowledge influenced their advocacy efforts and their children's access to necessary support.

I employed a phenomenological design because it placed caregivers' firsthand perspectives at the forefront, enabling a deeper understanding of their daily experiences. IPA invites a partnership between researcher and participant, where meaning unfolds through our shared interpretation of each caregiver's story. This approach aligned

perfectly with my goal to present IDEA not as a set of abstract rules, but as a lived reality that shapes how caregivers care for their children.

Data was collected from a purposive sample of 5–10 primary caregivers of children aged 3–18 who hold Individualized Education Programs (IEPs). Recruitment took place through an ABA clinic serving autistic children and through word-of-mouth referrals, also known as snowballing. Each participant engaged in a single, semi-structured interview, lasting approximately 30–60 minutes, conducted virtually according to their preference. I designed an interview guide to elicit detailed descriptions of encounters with schools and agencies, caregivers' understanding of their legal rights, and the practical steps they take to secure services.

The analysis followed the IPA framework outlined by Smith and Nizza (2022). First, interviews were transcribed verbatim and read repeatedly to foster immersion in each caregiver's account. Second, initial exploratory comments and emergent themes were noted, focusing on language that reflected participants' sense-making processes. Third, patterns across cases were identified, grouping related themes into superordinate categories. To make sense of the data, I moved back and forth between individual quotes and the bigger story, weaving them together to see how they reflect the broader experience of navigating IDEA. Along the way, I checked in with participants to confirm my interpretations, maintained a reflective journal to record my own biases, and discussed emerging insights with colleagues to ensure the findings were robust and reliable.

By centering caregivers' voices and employing a phenomenological methodology, I aimed to generate rich, actionable insights into the experiential and interpretative dimensions of navigating IDEA. These findings informed the development of targeted educational interventions and support services to strengthen caregivers' legal literacy and advocacy capacity, thereby promoting more equitable access to special education resources.

Definitions

Advocacy: Speaking and acting on behalf of another person to address their strengths, preferences, or needs (Wolfensberger, 1977). This study captures caregivers' active efforts to secure IDEA-mandated supports and services for their children.

Admission, Review, and Dismissal (ARD): The formal process that is often used in Texas where a student's eligibility for special education is determined, reviewed, and updated, typically resulting in the development or revision of an IEP (Texas Education Agency, 2023).

Autism Spectrum Disorder (ASD): Developmental condition characterized by challenges with social communication and restricted or repetitive behaviors (American Psychiatric Association, 2022).

Disability: In educational and legal contexts, disability is defined as a physical or mental impairment that substantially limits major life activities. Under IDEA, this includes conditions such as autism, intellectual disability, or other health impairments (U.S. Department of Education, 2025).

Down Syndrome: Genetic condition caused by a complete or partial extra copy of chromosome 21, which alters developmental pathways and is often associated with developmental and cognitive differences (National Down Syndrome Society, 2025).

Early Intervention: Services under IDEA Part C provided to infants and toddlers with disabilities (birth to age 2) and their families to support development during early childhood (U.S. Dept. of Education, 2025).

Empowerment: Enhancing individuals' self-efficacy, critical awareness, and capacity to act effectively (Holcomb-McCoy & Bryan, 2010). This study reflects caregivers' ability to advocate for their children's educational rights within IDEA.

Free and Appropriate Public Education (FAPE): FAPE mandates that schools deliver individualized and no-cost education and related services that are tailored to meet unique needs of students with disabilities, as stipulated by the IDEA (Yell et al., 2020).

Individuals with Disabilities Education Act (IDEA): The IDEA is a federal law ensuring eligible children with disabilities have access to special education, early intervention (Part C), and related services in the least restrictive environment (U.S. Department of Education, 2025).

IEP (Individualized Education Program): Legally binding document developed by educators and parents that outlines individualized educational goals, supports, and services for a child with a disability (Yell et al., 2020).

Inclusion/Inclusive Education: Educating students with disabilities alongside their non-disabled peers in general education classrooms with appropriate supports, promoting equity and participation (UNESCO, 2017).

Intellectual Disabilities: Significant limitations in intellectual functioning and adaptive behavior, originating before age 18 (Schalock et al., 2021).

Section 504 Plan: Under Section 504 of the Rehabilitation Act, qualified students with disabilities are entitled to accommodations and modifications in general education settings to ensure equal access to learning environments (U.S. Dept. of Education, 2025).

Special Education: Specially designed instruction, delivered at no cost, to meet the unique needs of students with disabilities, as required by IDEA (20 U.S.C. § 1401).

Assumptions

In this study, I worked from a few core assumptions that, while I cannot verify them, are essential for its overall credibility. One is that participants would be open and thoughtful when sharing their experiences with IDEA. Because phenomenological research relies heavily on the richness of personal stories, the depth and honesty of the interview data depended on caregivers' willingness to recall past events accurately and discuss potentially sensitive topics candidly (Smith & Nizza, 2022). If they held back or misremembered, there was a risk of missing the nuanced insights into how they understood procedural safeguards and the real challenges they faced when advocating for their children.

Second, the study assumed that I could effectively bracket personal biases and preconceptions during data collection and analysis. In interpretative phenomenological analysis, the investigator serves as the primary instrument of analysis, and the co-construction of meaning between researcher and participant is vital (Smith & Nizza, 2022). By maintaining reflexive awareness, through journaling and peer debriefing, it

was presumed that I could distinguish between participants' intended meanings and their interpretative lens. This assumption was critical to ensure that themes emerged from the data rather than from external theoretical or personal agendas.

Third, it was presumed that the phenomenon of interest, caregivers' navigation of IDEA, could be meaningfully captured through semi-structured interviews with a purposive sample of 5–10 participants. I recognize that no single study can capture every possible experience, but I'm confident that interviewing 5–10 caregivers from different backgrounds surfaced enough common themes to be meaningful (Creswell & Creswell, 2017). I also assumed that participants would have at least a basic understanding of IDEA terms, such as IEP and due process, so they could describe their journeys in a way that aligned with the framework. If someone isn't clear on those concepts, their stories might reflect misunderstandings that could muddy the link between legal awareness and advocacy. Being upfront about these assumptions helps keep the research transparent and allows readers to judge the findings within the proper context.

Scope and Delimitations

This study narrowed its focus to the lived experiences of primary caregivers of children aged 3–18 who held Individualized Education Programs (IEPs) under IDEA, specifically examining how their awareness of legal rights influenced advocacy behaviors and access to services (Ewick & Silbey, 1998; Zimmerman, 1995). The delimitations of this study included the focus on children ages 3 to 18. This range was selected because it encompasses the continuum of formal schooling under IDEA, beginning with preschool services at age three and extending through the completion of secondary education.

Limiting the study to this range ensured alignment with the educational contexts in which parents are legally recognized partners in decision-making and advocacy. Excluding children younger than three and older than eighteen narrowed the scope to a developmental and policy period where family-school collaboration is most consistently structured and comparable. By concentrating on caregivers' legal consciousness and empowerment processes, the research addressed three interrelated aspects of the problem: (a) informational, emotional, and systemic barriers to understanding IDEA (Harry & Ocasio-Stoutenburg, 2021; Sapiets et al., 2023); (b) the ways self-efficacy and critical system knowledge translated into concrete advocacy actions (Conger & Kanungo, 1988; Foster-Fishman et al., 1998); and (c) the downstream effects of these dynamics on children's timely access to appropriate educational supports (Szlamka et al., 2022). This specific emphasis was chosen to address a critical gap in the literature, as prior studies have documented advocacy training outcomes (Burke et al., 2022) and systemic barriers (Mann & Gilmore, 2023); however, they have not directly linked legal awareness to advocacy efficacy.

To maintain clarity and feasibility, the study excluded caregivers of children without IEPs, service providers, and educational professionals. It also omits broader theoretical frameworks, such as Bronfenbrenner's ecological systems theory or family systems theory, that, while relevant to child development, fall outside the immediate scope of legal consciousness and empowerment as applied to IDEA navigation. By delimiting the sample to 5–10 caregivers recruited through the ABA clinic, I ensured in-

depth phenomenological engagement while acknowledging that caregivers' experiences in different jurisdictions or with children outside the chosen age range may differ.

Although the findings were contextually bound to caregivers' narratives of IDEA engagement, they can be applied to similar settings. Insights into how limited procedural literacy curtails advocacy efforts may inform interventions in other special-education contexts or for caregivers navigating related disability rights laws. Readers and practitioners can assess the applicability of these results to their own settings by comparing participant characteristics, policy environments, and the availability of support services. In this way, the study struck a balance between a focused inquiry into a well-defined problem and the potential for broader relevance to developmental psychology and special education practice.

Limitations

This study's phenomenological design and purposive sampling of 5–10 caregivers naturally limited the breadth of perspectives represented and the transferability of findings to broader populations. Focusing on caregivers of children aged 3–18 with IEPs, the research excluded families whose children receive services under different eligibility criteria or who have not yet entered the special education system. Since this approach dove deeply into each person's story, the detailed insights I uncovered may not be applicable to every caregiver working with IDEA (Creswell & Creswell, 2017; Smith & Nizza, 2022).

Dependability was also constrained by the single-interview format and the cross-sectional nature of data collection, as caregivers' perceptions and advocacy behaviors

may evolve or differ across different policy contexts. Participant self-reporting introduced potential biases, including selective memory, social desirability, and varied interpretations of IDEA terminology. When recounting emotionally heightened moments, caregivers could have inadvertently omitted or altered portions of their stories, which can impact the authenticity of the data (Smith & Nizza, 2022). Likewise, as the primary analyst in an IPA study, my own assumptions and theoretical leanings could steer which themes I noticed and how I made sense of them. By being transparent and acknowledging these potential biases, I maintained analytical rigor and ensured that the findings genuinely capture participants' lived experiences.

To strengthen the study's trustworthiness, I used several complementary techniques. I kept a reflexive journal and practiced bracketing, which allowed me to spot and set aside my own assumptions as I worked through the data (Smith & Nizza, 2022). I also shared emerging thematic summaries with participants, using member checking, to ensure that my interpretations genuinely reflect their experiences and to reinforce the study's credibility (Creswell & Creswell, 2017).

Peer debriefing sessions with colleagues provided external feedback on emerging themes, while a detailed audit trail of methodological decisions bolstered dependability and confirmability. Finally, by providing thick, contextualized descriptions of participants' narratives, readers can assess the applicability of the findings to other settings and determine their transferability.

Significance

This study offered multiple contributions to developmental psychology, special education practice, and the broader goal of positive social change. First, by integrating legal consciousness theory with empowerment theory, it advanced disciplinary understanding of how caregivers' internalized perceptions of law (Ewick & Silbey, 2002; 1998) and their evolving self-efficacy (Conger & Kanungo, 1988; Foster-Fishman et al., 1998; Zimmerman, 1995) jointly shape advocacy behaviors under IDEA. Past research has either documented systemic barriers (Mann & Gilmore, 2023; Sapiets et al., 2023) or measured outcomes of advocacy training (Burke et al., 2022). This study filled a critical gap by tracing the cognitive and emotional pathways through which legal knowledge becomes actionable. In doing so, it enriched theoretical models in developmental psychology by situating caregiver advocacy within the lived, interpretive frames that guide everyday decision-making.

Second, the phenomenological design yielded richly textured data on caregivers' firsthand experiences, providing empirical overtones to conceptual debates around parental agency. Qualitative insights into how parents perceive IDEA as an empowering resource or a procedural burden can inform future scale development, as well as mixed-methods work seeking to quantify legal consciousness. By teasing out themes such as "choice" versus "coercion" in caregivers' narratives and their interactional expertise during IEP meetings, this work provides a springboard for crafting targeted measurement instruments. Those tools can then be tested in larger quantitative studies, melding the

richness of personal stories with the precision of psychometric analysis and opening up fruitful dialogue across fields.

From a practice perspective, these findings can directly inform the design of caregiver-focused interventions. If, for example, parents consistently report confusion around due-process timelines or consent requirements, special education support services can develop targeted workshops or one-page “rights checklists” tailored to identified pain points. Empowerment theory’s intrapersonal, interactional, and behavioral dimensions (Foster-Fishman et al., 1998; Zimmerman, 1995) provide a ready framework for structuring such programs: building parents’ confidence, deepening their understanding of procedural safeguards, and offering concrete advocacy strategies. Educators and school-based social workers can utilize these insights to co-create training sessions that enhance knowledge and promote real-time application (e.g., mock IEP simulations).

At the policy level, this research highlighted how gaps in legal consciousness contribute to inequitable access to services, particularly for families facing socioeconomic, language, or cultural barriers (Rossetti et al., 2021). State education departments and advocacy groups can utilize these findings to update their parent notification materials under IDEA, ensuring the language is clear, culturally relevant, and accessible to all families. Moreover, by documenting instances where caregivers felt their rights were ignored or inadequately met, the study supports legislative advocacy for stronger accountability measures, such as mandatory rights-literacy modules for school staff or periodic audits of district-level compliance with procedural safeguards.

This study also aimed to have a wider community impact, reflecting Walden University's dedication to positive social change. By helping caregivers gain a clearer grasp of their legal rights, the stage has been set for fairer, more balanced partnerships between families and schools, partnerships that research confirms are crucial for children's academic success and emotional well-being (Epstein, 2002). Strengthened parent-advocates can, in turn, mentor peers, forming grassroots support networks that amplify the collective voice and catalyze systemic improvements. This ripple effect exemplifies the "scholar-practitioner" model: rigorous inquiry produces practical tools that, when disseminated through community channels, foster greater resilience and inclusion for families of children with disabilities.

The study's scope, while intentionally focused, also offers transferable lessons for related contexts. Professionals working with families navigating Medicaid waivers, early intervention programs, or Section 504 accommodations can adapt the empowerment-legal consciousness framework to assess and bolster clients' capacity to engage with these systems. Researchers working in different states or even other countries within the field of special education law can apply these insights into how stories and empowerment shape advocacy in their own legal and cultural settings. By being transparent about the methods, this study encourages others to compare results and adapt the approach to their unique environments, thereby widening its practical impact.

Ultimately, this study highlighted the moral necessity of focusing attention on caregivers' perspectives in policy-making processes. Highlighting how parents make sense of IDEA and the emotional labor advocacy entails. Harry & Ocasio-Stoutenburg

(2021) called attention to the moral duty of schools and agencies to simplify legal processes and honor family expertise. By documenting these lived experiences in scholarly form, the dissertation asserts that meaningful reform must begin with listening and transforming caregivers from passive subjects of policy into active partners in designing systems that truly serve their children. In summary, this study advanced theory by weaving together legal consciousness and empowerment constructs, enriching measurement practices through phenomenological insights, guiding practitioners in crafting targeted support, informing policy on equitable rights literacy, and fostering positive social change by amplifying caregiver agency. Its contributions resonate beyond the immediate sample to any context where legal frameworks intersect with familial care, offering a research model that is both academically rigorous and socially engaged.

Summary

This chapter has introduced the pressing issue that many caregivers of children with disabilities navigate IDEA without a full understanding of their legal rights, which limit their ability to secure timely and appropriate services (Ewick & Silbey, 1998; Zimmerman, 1995). Drawing on legal consciousness theory and empowerment theory, the study's purpose and research questions were framed within a constructivist, phenomenological paradigm that foregrounds caregivers' firsthand narratives (Conger & Kanungo, 1988; Ewick & Silbey, 2002; Smith & Nizza, 2022). I outlined the study's scope, focusing on primary caregivers of school-aged children with IEPs, and acknowledged the delimitations related to sample size, self-report bias, and contextual boundaries (Creswell & Creswell, 2017). Key assumptions and limitations were

discussed alongside strategies for ensuring trustworthiness, including reflexive journaling, member checking, and peer debriefing (Smith & Nizza, 2022). Ultimately, this research has the potential to deepen our theoretical understanding of caregiver advocacy, inform the development of practical support programs for families, and guide policy reforms that promote equity and foster positive social change (Epstein, 2002; Szlamka et al., 2022).

Chapter 2 will build on this foundation by conducting a comprehensive review of the literature, organized around six focal areas directly tied to the research questions: (a) caregivers' legal knowledge and consciousness; (b) informational, emotional, and systemic barriers to IDEA awareness; (c) empowerment processes and actual advocacy behaviors; (d) contextual and demographic influences on legal consciousness and empowerment; (e) impacts on service access and child outcomes; and (f) existing intervention and policy responses. Within each section, the review will synthesize theoretical and empirical work, identify persistent gaps, and justify the specific hypotheses and measurement strategies that will guide our phenomenological inquiry. By situating the study within the broader scholarly conversation, Chapter 2 will refine the conceptual framework and pave the way for the detailed methodological plan presented in Chapter 3.

Chapter 2: Literature Review

I aimed to explore real-life experiences of caregivers of children with disabilities, addressing obstacles they face when attempting to understand and use IDEA protections and examining how legal knowledge gaps impact their advocacy efforts and day-to-day caregiving. Via caregivers' own stories, the research shows thought processes and empowerment journeys that drive effective advocacy, offering insights regarding informing policy, practice, and future scholarship. This problem is significant because many caregivers of children with disabilities navigate the IDEA without a clear understanding of their legal rights, which can limit their ability to secure timely and appropriate educational services. Literature suggests caregivers often encounter informational, emotional, and systemic obstacles when engaging with special-education systems. Studies have documented fragmented service delivery and bureaucratic delays in early intervention, the emotional toll of sustained advocacy efforts, and measurable gains in self-efficacy following structured training programs. The legal consciousness and empowerment theories were used for understanding how caregivers interpret the IDEA and translate interpretations into actions; these theories have rarely been applied together to examine perceptions and practices.

There remains a lack of research regarding how specific gaps in caregivers' legal knowledge, such as misunderstandings involving procedural safeguards or entitlement provisions, directly impact their capacity to advocate and secure services in the context of the IDEA. While sources have separately addressed outcomes of advocacy training and systemic barriers families face, few studies have probed narratives caregivers use to make

sense of the IDEA or real-world advocacy behaviors and service outcomes. This gap limits interventions that build confidence and enhance procedural literacy in ways that meaningfully improve access to supports. This chapter includes an outline of the theoretical foundation, conceptual framework, and studies that inform this investigation. First, I reviewed legal consciousness and empowerment theories as lenses for interpreting caregivers' experiences. Next, I examined the current state of knowledge regarding caregivers' legal awareness of the IDEA and barriers they face. I then explore empowerment processes and advocacy behaviors, the influence of contextual and demographic factors, downstream impacts on children's service access and developmental outcomes, and existing intervention and policy responses. By addressing these six focal areas, I established the groundwork for phenomenological methods that are detailed in Chapter 3 and highlighted this study's unique contributions.

Literature Search Strategy

I used a thorough step-by-step approach to gathering literature, ensuring I addressed both key theoretical foundations and the latest empirical studies on the topic. I used the following databases: the Walden University Library, Taylor & Francis Online, JSTOR, SAGE Journals, and Google Scholar. These databases were selected because for a balance of peer-reviewed journals, book chapters, and interdisciplinary research including education, psychology, and sociolegal studies.

I used the following key terms in this study: *disabled children, children with disabilities, caregivers of disabled individuals, Individuals with Disabilities Education*

Act, IDEA, special education law, parent advocacy, caregiver empowerment, legal consciousness, service access, procedural safeguards, and barriers to IDEA.

I approached the search in stages, like Creswell and Creswell suggested for qualitative reviews. I began with broad searches via the Walden University Library and sifted through the hundreds of results by reviewing titles and abstracts. From there, I used more specific followup searches that better matched my study's focus. Once key sources were identified, reference lists were mined via snowballing for additional relevant studies, which in turn guided further database queries.

All sources were published between 2018 and 2023 for empirical studies, with seminal theoretical works that were included regardless of their publication date. I excluded conference proceedings, editorials, and sources that did not address caregivers' direct experiences with the IDEA. Each database search was documented with recording date, search string, and number of results to maintain an audit trail and ensure transparency. By distinguishing between specific and broad terms, I maintained a balanced focus in order to address the topic.

Theoretical Foundation

Ewick and Silbey (1998) stated people bring legal ideas into their everyday lives, not just into courtrooms. Ewick and Silbey (2002) sharpen this insight by describing law as both a source of personal power, what they call choice, and a set of external constraints, coercion. In this study, I used the legal consciousness theory to explore how caregivers talk about and experience the IDEA.

The empowerment theory, which has its roots in community psychology, helps explain how people transition from knowing their rights to applying them in real-life situations. Foster-Fishman et al. (1998) stated confidence, system knowledge, and concrete advocacy steps feed into one another. Three interrelated dimensions are intrapersonal (self-efficacy and perceived control), interactional (critical knowledge of systems), and behavioral (advocacy actions), demonstrating growth in one reinforces gains in the others. In the context of IDEA navigation, the empowerment theory helps explain why some caregivers feel confident and capable in terms of advocating for services once they recognize their rights. By contrast, others, even with similar knowledge, may struggle to act. By using these theories, I trace caregivers' interpretations of IDEA and lived advocacy practices.

Building on legal consciousness and empowerment theories, this study advances three core propositions. First, drawing on Ewick and Silbey's (1998, 2002) work, we propose that caregivers' narrative frames, whether they perceive IDEA as an enabling "choice" or as a constraining "coercion," fundamentally shape their engagement with procedural safeguards. In other words, those who frame IDEA as a resource for agency (choice) will be more likely to proactively approach IEP meetings and due-process options, whereas those who experience it primarily as a bureaucratic burden (coercion) may adopt a more passive or avoidant stance. This proposition assumes that narrative framing is identifiable in caregivers' language and sufficiently stable to influence behavior (Ewick & Silbey, 1998).

Second, empowerment theory offers complementary propositions regarding how legal awareness translates into action. Conger and Kanungo (1988) describe empowerment as the integration of meaningful participation, critical system knowledge, and enactment through concrete behaviors. Zimmerman (1995) refines this into three interrelated dimensions: intrapersonal (self-efficacy), interactional (understanding systems), and behavioral (advocacy steps). Foster-Fishman et al. (1998) empirically demonstrate that growth in one dimension reinforces gains in the others. From this perspective, it is hypothesized that caregivers who develop a strong intrapersonal sense of efficacy will seek out and utilize IDEA information more effectively (interactional dimension) and then engage in tangible advocacy behaviors, such as requesting evaluations or facilitating service negotiations. An underlying assumption is that these dimensions can be distinguished in interview data and coalesce to produce observable advocacy practices.

Third, integrating these theoretical strands leads to a hypothesis about mediation and outcomes: interactional empowerment (critical awareness of procedural safeguards) mediates the relationship between narrative frame orientation and behavioral empowerment, resulting in more effective service development and access. Szlamka et al. (2022) found that empowered families can better shape the design of services. We extend this insight by suggesting that caregivers' legal consciousness, filtered through empowerment processes, drives their ability to influence IEP outcomes and early intervention plans. This model assumes that service development efforts are responsive to

parental advocacy and that improved advocacy efficacy leads to measurable differences in children's educational supports.

Together, these propositions outline a clear pathway, from how caregivers discuss IDEA, through their sense of personal and system-level empowerment, to their specific advocacy actions and the service outcomes they achieve. This chapter will expand on these propositions, situating them within the broader literature and detailing the specific qualitative hypotheses and analytic strategies to test this combined theoretical framework.

Legal consciousness theory has been applied across various socio-legal contexts to reveal how people incorporate legal ideas into their daily lives. Ewick and Silbey's (1998) foundational work demonstrated that individuals draw on legal narratives, even in informal settings, to interpret rights and responsibilities, a process further elaborated in their discussion of "choice" versus "coercion" (Ewick & Silbey, 2002). In the special education arena, these insights have been utilized to understand how parents navigate their rights under the IDEA, highlighting the role of narrative frames in shaping decisions about when and whether to request formal IEP meetings or due process hearings (Rossetti et al., 2021). By foregrounding caregivers' storytelling, past studies have linked the framing of law to concrete engagement with educational institutions, setting a clear precedent for applying legal consciousness theory in the current research.

Empowerment theory offers a complementary lens for examining how legal awareness translates into action. Conger and Kanungo (1988) articulated empowerment initially as a process involving meaningful participation, critical awareness of resources, and enactment through concrete behaviors. Zimmerman (1995) refined this model into

three dimensions: intrapersonal, interactional, and behavioral. Foster-Fishman et al. (1998) provided empirical support, demonstrating that enhancing one dimension, such as self-efficacy, can spur growth in the others. More recently, Szlamka et al. (2022) applied empowerment theory to individuals with developmental disabilities, showing that empowered families can influence service design and improve their access to services. These studies confirm that empowerment theory can be operationalized in contexts where lay individuals, specifically, caregivers, must marshal knowledge and confidence to navigate complex service systems, just as they must under IDEA. Legal consciousness and empowerment theories have been combined to study advocacy in health and social services, but their joint application to IDEA navigation remains limited. For example, research on mental-health parent advocates has mapped empowerment processes (Smith-Young et al., 2022) without fully integrating how their legal narratives shape these processes. Conversely, studies of legal consciousness in disability law highlight narrative frames but seldom trace the downstream steps that lead to empowerment and action. The current study builds on prior applications in related fields by marrying these theories. It extends them into the special-education context, offering a more holistic view of how caregivers' interpretations of IDEA inform, and are informed by, their evolving advocacy behaviors.

The rationale for selecting these theories lies in their complementary strengths. Legal consciousness theory captures the interpretive work caregivers do to make sense of IDEA's procedural safeguards. In contrast, empowerment theory explains how those interpretations translate into self-efficacy, system knowledge, and actionable strategies.

Both frameworks have been empirically validated in community and organizational settings (Conger & Kanungo, 1988; Foster-Fishman et al., 1998; Szlamka et al., 2022), aligning with the study's phenomenological design, which seeks to understand meaning-making and lived experiences (Smith & Nizza, 2022). They provide a robust conceptual foundation for examining the pathway from narrative framing to advocacy action. They are well-suited to address the identified gap in linking caregivers' legal awareness to their capacity to secure IDEA-mandated services.

In this study, I combined legal consciousness theory and empowerment theory to illuminate how caregivers make sense of the IDEA and translated that understanding into action. Legal consciousness theory posits that individuals draw on legal meanings in everyday life, framing law as either a tool of agency ("choice") or a source of constraint ("coercion") based on their narratives (Ewick & Silbey, 1998, 2002). In the present research, these frames serve as the lens through which we examine caregivers' stories about IEP meetings, procedural safeguards, and due-process options. By asking, "How do caregivers describe their rights under IDEA, and what stories do they use to construct those rights?" this study extends legal consciousness theory into the special-education domain, testing whether these narrative orientations predict differences in advocacy behaviors and service outcomes.

Empowerment theory complements this perspective by explaining how knowledge and self-perception fuel concrete advocacy steps (Conger & Kanungo, 1988; Zimmerman, 1995). Foster-Fishman et al. (1998) demonstrated that intrapersonal (self-efficacy), interactional (system knowledge), and behavioral (advocacy actions)

dimensions mutually reinforce one another in community settings. In applying empowerment theory here, we investigate whether caregivers who articulate stronger “choice” frames also report higher self-efficacy and a greater propensity to engage in procedural safeguards, such as requesting IEP revisions or filing formal complaints. The research questions directly probe these links, asking what barriers limit caregivers’ legal awareness and how gaps in that awareness hinder empowerment processes and diminish the efficacy of advocacy.

By integrating these theories, this study challenges existing research that treats narrative framing and empowerment as separate silos. Szlamka et al. (2022) demonstrated that empowered families can shape service development; however, they did not investigate how legal narratives lay the groundwork for empowerment to occur. Likewise, studies of IDEA awareness often document low knowledge levels without tracing how this lack of awareness undermines caregivers’ confidence or actions. The research question builds on these gaps, proposing a mediated model in which narrative frames influence empowerment dimensions, which, in turn, drive specific advocacy behaviors and ultimately, children’s access to support.

This dual-theory foundation grounded the study’s phenomenological design, centering caregivers’ voices, and positions the research to refine legal consciousness and empowerment theories. By mapping the journey from story to self-efficacy to service access, the aim is to provide a more nuanced account of advocacy under IDEA than has been presented in prior work. The next chapter will review empirical studies and

theoretical treatments in each domain, setting the stage for the methodological approach that brings these questions to life.

Literature Review

Before examining the systemic barriers and advocacy strategies that shape special education experiences, it is essential to consider the foundation on which all caregiver engagement rests: their legal knowledge and educational rights consciousness. This theme examined how caregivers comprehend, interpret, and apply legal frameworks, such as the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act, that govern their children's access to education. Legal knowledge is not simply the memorization of statutes but a lived, evolving awareness shaped by historical precedent, personal experience, cultural context, and how institutions communicate (or obscure) information. By starting here, this review foregrounds the legal literacy that underpins effective advocacy, positioning caregivers not only as recipients of services but also as active agents in securing and exercising their rights within complex educational systems. The following discussion integrates historical milestones, such as *Brown v. Board of Education*, theoretical perspectives on empowerment and legal consciousness, and empirical insights into how caregivers acquire and enact their understanding of rights, laying the groundwork for the subsequent themes.

Caregivers' Legal Knowledge and Consciousness

The historical roots of educational equity shape how caregivers understand their legal rights and responsibilities. *Brown v. Board of Education* (1954), often discussed in

the context of racial segregation, also laid critical groundwork for disability rights and the fight for educational equity. By overturning “separate but equal,” the decision established that denying any child access to a quality public education constitutes a violation of civil rights. That principle set the stage for legislation like the Individuals with Disabilities Education Act (IDEA), which guarantees special-education services as a legal right rather than a privilege. For today’s caregivers navigating special education, *Brown v. Board* is more than history; it is a powerful reminder that inclusive schooling is non-negotiable. Yet, as Babik and Gardner (2021) note, policy victories do not erase societal biases toward disability; structural attitudes continue to shape whether these rights are fully realized. Similarly, Ahram, Voulgarides, and Cruz (2021) found that despite IDEA’s nationwide mandate, implementation varies dramatically by region, socioeconomic status (SES), and racial demographics, leaving many caregivers in marginalized communities with only partial access to promised supports. These disparities mirror the uneven enforcement of *Brown*, illustrating that both landmark rulings and federal statutes require vigilant, informed advocacy to translate legal principles into lived reality. Connecting current struggles for caregiver empowerment to these intertwined histories highlights how broader cultural, demographic, and structural contexts continually shape legal knowledge.

Empowerment theory offers a valuable lens for examining how caregivers interact with special education systems. Conger and Kanungo (1988) first described empowerment as not merely the transfer of power but an ongoing process of building confidence, acquiring resources, and navigating systemic constraints. Although their

model emerged from organizational behavior, it has become a cornerstone for examining how individuals feel and act empowered across settings, including education. True empowerment, they argue, requires more than self-belief; it depends on access to tangible tools and supportive environments, or, conversely, on overcoming restrictive ones. When applied to caregivers' legal knowledge, this framework clarifies how parents' sense of their rights and capacity to act form within the complex ecosystem of special education. Sullivan and Osher (2019) highlight that for many families, particularly those facing socioeconomic and racial inequities, IDEA functions as a "double bind": it promises equity but often embeds procedural and cultural hurdles that disproportionately burden marginalized parents. Babik & Gardener (2021) similarly emphasized that demographic factors such as income, education level, and community context influence family and school perceptions of disability and inclusion. By integrating Conger and Kanungo's theoretical framing with these empirical insights, this study treats empowerment as both a mindset and a set of material conditions that remain unevenly distributed despite the universal language of the law.

Methodological frameworks also play a critical role in guiding qualitative inquiry. Creswell and Creswell (2017) provided a clear roadmap for crafting qualitative studies that align with a researcher's philosophical stance and aims. Their guidance on naming core constructs, tying them to research questions, and choosing methods that fit the inquiry served as a backbone for work seeking to capture nuanced lived experience in education. This focus on methodological "fit" echoed Merriam, Tisdell, & Stuckey-Peyrot's (2025) insistence that qualitative research situate participants' voices within the

cultural, social, and political contexts that shaped meaning. Patton (2015) reinforced the point by underscoring the value of purposeful sampling and careful design to ensure that qualitative findings are both credible and useful. Lincoln and Guba's (1985) criteria for trustworthiness emphasized the ethical and procedural alignment required for robust interpretive work. For the present study, the combination of Creswell's structural clarity, Merriam's contextual grounding, Patton's design principles, and Lincoln and Guba's trustworthiness framework supports the decision to explore caregiver legal consciousness through a thematic synthesis of existing literature. Informed by this framing, the review centers caregiver experiences not as isolated events, but as socially and legally embedded phenomena shaped by intersecting systems of power, while reinforcing the importance of transparency in linking conceptual frameworks to lived realities.

Legal consciousness expands this discussion by examining how people live and interpret the law in their daily lives. Ewick and Silbey's (1998, 2002) work on legal consciousness deepens this view by showing that knowing the law is not simply about memorizing statutes but about how people live and breathe daily legal ideas. They described three ways we "engage the law": standing before the law as novices, moving with the law through routines, and pushing back against the law when rules feel unjust. These modes help explain how caregivers piece together their understanding of IDEA, often drawing on stories from friends, past encounters with bureaucracy, or community knowledge. Similarly, Morrill et al. (2020) traced developments in legal consciousness scholarship, underscoring how community contexts and shared experiences can influence the ways people perceive and engage with the law, especially for marginalized

groups. Sullivan and Osher (2019) further found that systemic inequities often determined whether individuals felt confident challenging institutions or resigning themselves to systemic limitations. For parents of children with disabilities, these informal and relational sources of legal knowledge can be as influential as formal training or legal documents, filtering through their social and economic backgrounds, racial identities, and shared histories. When read together, these works underscore why some caregivers confidently assert their rights. In contrast, others remain hesitant; true empowerment requires the information and the supportive environment to act on it.

Interpretative Phenomenological Analysis (IPA) offers an additional foundation for understanding caregivers' experiences. Smith and Nizza (2022) advanced IPA to explore how individuals make meaning of complex, deeply personal experiences, especially within systems that often marginalize or disempower them. Their approach emphasizes understanding how people interpret their world within their context, making it a powerful fit for studying caregiver experiences under IDEA. This resonates with Pietkiewicz and Smith's (2014) refinement of IPA, which stressed the importance of reflexivity and researcher awareness in capturing participants' lived realities without imposing external assumptions. Larkin et al. (2019) built on this by illustrating how IPA can be applied in socially complex, power-imbalanced contexts to reveal the interplay between personal meaning-making and systemic constraint. In the present study, IPA provides a conceptual bridge for analyzing how caregivers internalize and act on their legal rights, particularly when filtered through emotional labor, cultural histories, and interactions with school systems. By pairing IPA's focus on meaning-making with legal

consciousness theory, this review reframes legal knowledge not as a static checklist but as a layered, evolving consciousness shaped by identity, emotion, and social interaction, often revealing gaps between legal intent and lived reality.

Research on school practices further highlights how deficit perspectives affect parental advocacy. Shah et al. (2015) dug into how schools and policymakers often see disability, and by extension, parents, through a deficit lens, framing caregivers as passive recipients of professional decisions instead of true partners. That mindset can seriously dent parents' legal confidence and motivation to learn about IDEA rights, because they're not encouraged to speak up or trusted to know what's best for their children. Shah and colleagues championed a shift toward a strength-based approach, treating families as experts in their own right. This aligns with Harry et al. (2005), who found that deficit-based assumptions are especially pronounced for families from racially and culturally diverse backgrounds, often leading to misinterpretation of parental involvement as apathy rather than systemic exclusion. Similarly, Connor et al. (2008) argued that deficit perspectives are embedded within traditional school cultures and practices, and that a disability study and inclusive education framework is needed to challenge these assumptions and re-center family expertise. Together, these works remind us that understanding the law is only half the battle; parents also need school cultures that welcome their input and respect their expertise.

Caregivers' sense of inclusion often hinges on school practices and policies. Sandoval et al. (2021) took us inside schools to show how their policies and practices shape whether caregivers feel truly included or left alone. They point out that while

districts might talk a big game about inclusion, it often ends up as a box to tick rather than an ongoing partnership with families. For parents, especially those juggling disability and systemic bias, inclusion means constantly negotiating for access, a voice at the table, and tangible equity in their child's education. This mirrors Trainor (2010a), who documented how the absence of authentic collaboration undermines caregivers' ability to engage fully in special education decision-making, even when formal rights are in place. Likewise, Fish (2008) found that school staff often held narrow interpretations of parental involvement, limiting participation to formal meetings rather than ongoing, shared decision-making. When schools fail to back up their promises with genuine support, parents often bear the full weight of advocacy, even if they don't feel prepared. Regarding legal consciousness, these findings reinforce that caregivers' sense of their rights is forged in the gap between institutional rhetoric and the lived classroom experience.

Every day, barriers to advocacy reveal how IDEA is experienced unevenly across families. Rossetti et al. (2021) highlighted the everyday challenges parents face when advocating under IDEA. In interviews with 127 caregivers, collaboration with school staff, though required by law, often felt like a burden rather than a pathway to empowerment. Many parents described the process as emotionally exhausting and logistically daunting, especially when they lacked prior trust in the school system or access to additional resources. The study also revealed a clear socioeconomic divide: families with greater financial and social capital navigated the system more easily, while others encountered closed doors and resistance at multiple points throughout the process. These patterns aligned with earlier work. Lalvani (2012) found that parents from

marginalized backgrounds frequently encountered subtle gatekeeping that eroded trust and curtailed their ability to act on what they knew. Lo (2008) further demonstrated that language barriers exacerbated these inequities, making it more challenging for linguistically diverse families to access timely evaluations and services. Taken together, these studies suggested that knowing one's rights was not enough; how parents experienced and used those rights depended heavily on their social position and the culture of the local school.

Inclusive education has been widely studied from the perspectives of parents of children with disabilities. Shurr et al. (2023) conducted a comprehensive review of the literature on inclusive education from the perspective of parents raising children with intellectual disabilities, highlighting how "inclusion" is defined, enacted, and understood in different contexts. They demonstrated that inclusion has evolved beyond placing students in general education classrooms, emphasizing practical teaching strategies and ensuring access to challenging, yet appropriate, content. That historical shift mattered for caregivers working within IDEA because it underscored that inclusion was as much a legal and philosophical choice as a logistical one. Yet their review found that, despite widespread support for inclusion in theory, schools and families often held very different ideas about what it looked like in practice. Kurth et al. (2015) similarly found that while administrators endorsed inclusion rhetorically, structural barriers such as limited staffing and inadequate training limited meaningful implementation. Parents' insights tended to be scattered across studies rather than woven into a unified narrative, despite their perspectives being crucial for aligning school and home approaches. By highlighting

these gaps in definition and implementation, Shurr and colleagues remind us that proper legal awareness must grapple with the complex reality of inclusion, and whose voices are heard when we decide what it means for a child to truly belong.

Role of Law in Educational Advocacy

Legal frameworks, such as the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and the requirement for a Free and Appropriate Public Education (FAPE), have long underpinned special education in the United States. These statutes outlined the services students were entitled to and guided caregivers on how to fight, collaborate, and demand accountability. Individualized Education Programs (IEPs) and the right to inclusive classrooms weren't optional extras but legal guarantees. Still, many parents picked up on these rights in bits and pieces rather than through clear, structured guidance. That gap between legal promise and everyday reality echoed the lessons of *Brown v. Board of Education*, where court rulings did not instantly translate into equal treatment. Building on this idea, Shah et al. (2022) demonstrated how caregivers utilized their legal expertise to push back against exclusion, reframing advocacy as both a survival strategy and a source of empowerment. Similarly, Zirkel (2017) reviewed recent special education case law and found that while litigation outcomes often reaffirmed parental rights, the complexity and length of due process procedures discouraged many families from pursuing legal remedies, particularly those without legal representation. These insights reinforce that law translation into practice is uneven and often dependent on resources.

The Individuals with Disabilities Education Act (IDEA) outlines the provision of FAPE in terms of both procedural and substantive requirements. Yell et al. (2020) outlined how IDEA centers the provision of FAPE, requiring that eligible students receive individualized services through an IEP tailored to their needs. They emphasized that FAPE is not a singular guarantee but rests on two interconnected components: procedural and substantive requirements. Procedural protections include timely evaluations, parental participation, and transparency during IEP development, while substantive requirements focus on whether an IEP is designed to support meaningful academic and functional progress. Legal precedents, such as *Bd. of Educ. v. Rowley*, 458 U.S. 176 (1982), and *Andrew F. v. Douglas Cty. Sch. Dist. RE-1*, 580 U.S. 386 (2017), clarified that even when procedural steps are followed, districts may fall short if the IEP's content lacks ambition or specificity (Yell, Katsiyannis, & Collins, 2020). clarified that even when procedural steps are followed, districts may fall short if the IEP's content lacks ambition or specificity. Yell and colleagues argued that understanding this distinction is essential for caregivers seeking to advocate effectively and hold school systems accountable. Katsiyannis et al. (2021) further emphasized that districts often prioritize procedural compliance to avoid litigation while neglecting the substantive quality of services. This creates a disconnect between meeting legal checkboxes and meeting students' actual needs.

The legal foundation of FAPE has been shaped by decades of policy and litigation. Yell and Bateman (2019) traced the legal scaffolding of FAPE from its early origins under the Education for All Handicapped Children Act (EHA) through pivotal

Supreme Court decisions. In *Smith v. Robinson*, 468 U.S. 992 (1984), the Court described EHA as a “comprehensive scheme” that obligated states to fulfill constitutional responsibilities to students with disabilities. This included placing students in school and collaborating with parents to ensure that programs were designed to meet each child’s unique needs. The later rulings in *Bd. of Educ. v. Rowley*, 458 U.S. 176 (1982) and *Endrew F. v. Douglas Cty Sch. Dist. RE-1*, 580 U.S. 386 (2017), clarified that IEPs must be “reasonably calculated” to deliver more than minimal progress. While procedural compliance remained vital, Yell and Bateman emphasized that substantive educational benefit, not just process, would increasingly guide how FAPE was interpreted and applied. Baker (2019) added that shifting judicial interpretations have increasingly emphasized evidence-based instructional practices as a component of “appropriate” education, raising the bar for what districts must provide under the law.

Section 504 of the Rehabilitation Act highlights both the promise and pitfalls of disability law in practice. Lewis and Muñiz (2023) examined Section 504 of the Rehabilitation Act, which is intended to ensure fair access to accommodations, and found that its implementation was far from uniform. They demonstrated that the law’s broad eligibility rules, ambiguous structural guidelines, and reliance on outside evaluators often favored well-off, white families who could leverage cultural knowledge and additional resources to secure accommodations, even in borderline cases. Meanwhile, families with fewer resources or facing racial bias ran into roadblocks and skepticism from professionals. According to Lewis and Muñiz, this same legal flexibility could empower a family’s advocacy or leave them stuck, depending on their social standing. In practice,

racism, ableism, and classism often stacked barriers against marginalized families, while those holding multiple forms of privilege found the system more accessible. Skiba et al. (2016) documented similar disparities in discipline policy implementation, showing how vague policy language can allow bias to creep into decision-making, thereby exacerbating inequities for students with disabilities.

Educator perspectives also shape how inclusion is realized in classrooms. Werner et al. (2021) flipped the script by focusing on educators rather than caregivers. They explored how teachers' understanding of inclusion policies, the support they received from their schools, and their sense of efficacy influenced their attitudes toward inclusive classrooms. They found that teachers with stronger policy knowledge and solid backing from their school communities felt more confident and held more positive views about teaching students with disabilities. Yet, Werner and colleagues uncovered a significant shortfall: only about 21% of teachers had formal training in inclusion, and many admitted their grasp of the policies was shaky. Their work highlighted that for inclusion to move from idea to everyday reality, families and educators need solid legal literacy and real institutional support.

Even though laws like IDEA aimed to guarantee support for students with disabilities, chronic underfunding repeatedly got in the way of real-world impact. According to a 2018 Congressional Research Service report (Dragoo, 2018), federal contributions have never covered more than 15% of the national average per-pupil cost, nowhere near enough for districts to meet their legal commitments. That funding gap often landed on families' shoulders, especially those from marginalized backgrounds,

forcing them to navigate tangled systems with little help. Rossetti et al. (2021) found that parents of color were hit hardest, running into repeated obstacles when they tried to secure evaluations, services, or meaningful IEP outcomes. Meanwhile, systemic inconsistencies only widened the divide. Yell and Bateman (2020) noted that even the strongest legal texts were ineffective if districts lacked the necessary training, resources, or will to implement FAPE correctly. In practice, these shortcomings reminded caregivers that knowing their rights was only half the battle; schools also needed to follow through.

These laws, and the uneven way they were implemented in schools, demonstrated that caregiver advocacy was a constant negotiation between rights on paper and everyday realities. This sets up the next theme, where I examine the structural, cultural, and informational barriers that shaped how families accessed, understood, and acted upon those rights.

Barriers to Legal Awareness

While IDEA promised equal access to education, the lived reality for many families, particularly those from marginalized backgrounds, reveals a stark gap between legal rights and institutional practice. Caregivers frequently encounter unclear procedures, under-resourced schools, and disparities shaped by race, socioeconomic status, and geography (Liu et al., 2023; Smith-Young et al., 2022). These gaps are not random; they reflect more profound structural inequities embedded in the systems that uphold educational justice (Trainor, 2010b). This section examines three overlapping dimensions of this problem: first, the structural and spatial barriers that restrict access;

second, the emotional and relational burdens caregivers shoulder; and third, the inconsistent knowledge and support families receive when trying to advocate for their children. These systemic, interpersonal, and informational barriers function less as isolated challenges and more as interwoven forces that leave many families navigating educational systems alone and under-supported.

Research on parental involvement often highlights the gap between rhetoric and practice in schools. Hornby and Lafaele (2011) offered a foundational model for understanding the persistent gap between the rhetoric of parental involvement and its actual practice within schools. They argued that this disconnect is driven by interlocking individual, institutional, and societal barriers, ranging from parents' beliefs about their capabilities to systemic inequities in how schools engage with families. Despite the well-documented benefits of strong parent-school partnerships, such as improved student behavior, mental health, and teacher morale, these practices are not consistently implemented across schools. The authors noted that parents from working-class and racially minoritized backgrounds often lack access to the same informal networks and cultural capital that empower white, middle-class families to navigate school systems confidently.

Moreover, parents may internalize doubts about their ability to support their children's education, especially if they lack formal education or have negative experiences with institutions. Specific challenges, like behavioral concerns, disabilities, or poor school communication, often exacerbate these dynamics, leaving families feeling unwelcome or judged. Even when schools offer invitations to participate, parents'

perceptions of those invitations can vary dramatically based on context, past treatment, and trust. Hornby and Lafaele (2011) thus made clear that meaningful parental involvement is not just a matter of policy design; it is about shifting power, repairing relational harm, and ensuring that schools create spaces where all families can engage without fear, stigma, or systemic disadvantage. This is consistent with Hoover-Dempsey and Sandler's (1997) parental involvement model, which proposed that parents' engagement decisions are influenced by their personal role construction, perceptions of school invitations, and life context variables that enable or constrain participation.

Quantitative studies have also investigated the relationship between parental involvement and student achievement. Jones and Gansle (2010) compiled findings from multiple quantitative studies to investigate the relationship between parental involvement and student achievement. They reported a consistent positive link, primarily when parents focused on learning at home, reading with children, discussing school, and maintaining regular contact with teachers. However, the benefits were not evenly shared. Families with more time, resources, and know-how saw the most significant gains, while those facing economic or cultural hurdles found it harder to participate at the same level. The authors also noted that many schools relied on a one-size-fits-all engagement model, favoring parents who already fit institutional expectations. By quantifying both the payoff and the inequities of involvement, their meta-analysis underscored why removing structural barriers mattered, not just inviting participation, but ensuring its academic benefits reached all students. Similarly, Mapp and Kuttner (2013) demonstrated that high-impact family-school partnerships require deliberate strategies to reach marginalized

families, noting that relational trust was the strongest predictor of sustained engagement across diverse school contexts.

Despite efforts to improve parental involvement, many challenges persist. Hornby and Blackwell (2018) revisited this framework seven years later, finding that many of the original issues had persisted. Their updated analysis highlighted a continued gap between schools' rhetorical support for parental involvement and the practical absence of inclusive practices. They noted that schools often failed to recognize the lived realities of parents, especially those from underserved communities. As Hornby and Lafaele (2011) had observed earlier, "there is still more rhetoric than reality about family and school, working together as genuine partners" (p. 38). This lack of follow-through contributed to a climate of disillusionment where parents feel powerless or unqualified to challenge school decisions, further deepening legal knowledge gaps. This echoes Turnbull et al. (2015), who found that IDEA's procedural safeguards were often underutilized by families not because they lacked interest, but because they lacked accessible, comprehensible information on how to exercise those rights.

Access to legal knowledge also varies globally, reflecting differences in socioeconomic status and institutional structures. Kosunen and Rivière (2018) successfully expanded the conversation globally, demonstrating that critical procedural knowledge is often transmitted through informal networks that favor more privileged families, leaving others to navigate complex systems without a clear map. Their work underscored how access to this knowledge is tied to socioeconomic status and the relationships families have, or lack, with trusted intermediaries. Wagner (2022) found a

similar situation closer to home: parents with limited incomes and minority backgrounds often miss out on family-centered programs that teach the legal and procedural basics necessary to advocate effectively. Wagner also highlighted how these gaps can compound over time, as parents excluded early in their child's educational journey often remain on the margins when new opportunities arise. Together, these studies demonstrate that uneven legal awareness is not merely a matter of lacking information; it is a byproduct of institutional cultures that fail to foster trust or equitable partnerships. Fixing this means more than handing out brochures; it requires fundamental changes in how schools and families relate, how institutions hold themselves accountable, and how inclusive our structures truly are. This uneven distribution of procedural knowledge reinforces broader inequities in legal access and perpetuates cycles of disenfranchisement for families outside privileged networks.

Research on autism diagnosis highlights persistent racial, socioeconomic, and geographic disparities in access. Liptak et al. (2008) provided one of the earliest large-scale examinations of how racial, socioeconomic, and geographic disparities influence access to autism diagnosis and services in the United States. Analyzing national survey data, they found that children of color and those living in rural or low-income communities were significantly less likely to be diagnosed early or referred to services. These delays were often linked to systemic biases, provider assumptions, and the uneven distribution of diagnostic resources. Because early intervention is often the gateway to specialized educational support, delays in diagnosis can significantly alter a child's entire developmental trajectory. Liptak and colleagues emphasized that these inequities were

not simply the result of family-level barriers but reflected structural gaps in health and education systems that compound over time. This finding aligns with Magaña et al. (2013), who documented that Latino families faced prolonged wait times for autism diagnosis and lower rates of service utilization even after diagnosis, mainly due to language barriers, cultural stigma, and lack of bilingual providers.

Geographic disparities also shape access to autism services, with race and place intersecting to deepen inequities. Liu et al. (2023) brought a spatial focus to the problem by mapping the intersection of race and place in access to autism services. Using national GIS analyses, they identified “autism deserts”—areas where specialized support was scarce or nonexistent. Families of color bore the brunt of these gaps, contending not only with distance but also with the cumulative effects of racism and economic precarity. National patterns showed that Black, Hispanic, and American Indian/Alaska Native autistic children typically had fewer nearby resources than their white peers, with the sharpest disparities in micropolitan regions. Liu and colleagues argued that access meant more than a clinic within driving range; it also depended on whether systems were navigable, culturally responsive, and trustworthy. Their findings anchored the idea that legal rights to services were constrained by lived geography, not just what the law promised.

Cross-cultural research further illustrates how systemic barriers impact families. Makino et al. (2019) examined Japanese parents’ experiences navigating the autism diagnostic process, revealing a system marked by inconsistency, professional discomfort, and fragmented support. The study found that diagnostic pathways often varied by region, meaning that a child’s location could influence the quality and speed of their

diagnosis. Delivering the diagnosis was also a challenge for professionals, who frequently lacked adequate training, struggled with disclosure, and expressed uncertainty about connecting families to resources in a fragmented system (Jacobs et al., 2018; Penner et al., 2017). While best practice in pediatrics calls for family-centered care approaches that position families as experts in their child's needs and link them to appropriate supports, Makino and colleagues found that this ideal was rarely realized. Instead, gaps in provider knowledge, limited coordination across systems, and variable access to family-centered care undermined trust and timely service delivery. These patterns align with broader findings in the literature, which suggest that geographic disparities, professional gatekeeping, and procedural opacity exacerbate legal access barriers, leaving caregivers to navigate systems that do not consistently recognize or value their expertise.

The emotional toll of advocacy is another barrier families face. Dugdale et al. (2021) provided a rich qualitative account of the emotional labor that autistic mothers undertake as they navigate diagnostic and educational systems. Their findings underscore the deep affective toll of advocating for their children within environments that are often unresponsive or dismissive. Participants in their study consistently described feeling misunderstood, judged, or dismissed by professionals, a dynamic frequently linked to their autistic traits. Many reported being praised for their calmness or ability to “cope well,” which professionals misinterpreted as a sign of a lack of need for support. This misunderstanding often led to service denial, even when mothers clearly articulated their needs. Dugdale and colleagues also noted that autistic mothers usually masked their

distress to meet professional expectations, a dynamic that perpetuated professional misunderstanding and emotional harm. One poignant theme was the mismatch between emotional experience and facial expression, often leading professionals to underestimate their needs. Moreover, sensory needs, particularly during pregnancy, and stigmatized assumptions about parenting abilities contributed to feelings of withdrawal and internalized doubt. These findings suggest that emotional barriers are not incidental, but deeply embedded in the institutional cultures that families must navigate, with profoundly negative consequences.

Caregivers in Canada also report layered barriers when navigating autism-related services. Smith-Young et al. (2022) painted a vivid, multi-layered picture of the hurdles Canadian parents face when securing autism-related services. Their study revealed five overlapping challenges: tight schedules, financial pressure, inconsistent service availability, gaps in procedural knowledge, and profound emotional exhaustion. One parent said bluntly, “We had to quit work to be more involved” (p. 7), pointing to the steep costs of private assessments and therapy travel. Beyond these practical struggles, caregivers felt worn down by what they saw as a lack of understanding from providers. Stigma, gatekeeping, and inconsistent diagnostic practices only made things more complicated. Strikingly, even those with backgrounds in psychology or child development could not fast-track support, underscoring that the real roadblocks lay in broken systems, not in parents’ willingness or readiness. Smith-Young and colleagues demonstrated that institutional inefficiencies, rather than caregiver apathy, were the

primary cause of the widest cracks when navigating a complex legal and procedural maze.

Long-term analyses consistently reinforce that systemic structures, rather than isolated gaps, drive disparities in service access. Dallman et al. (2021) compiled decades of research on access to allied health services for children with developmental disabilities, revealing that inequities persisted across various conditions, regions, and service pathways. In other words, the problem looked baked into the structure of systems rather than the result of a few policy gaps. Wallace-Watkin and Waddington (2023) echoed this in a more recent review, highlighting familiar trouble spots: provider shortages, fragmented referral routes, and policy loopholes that continue to disadvantage marginalized families. These persistent service barriers mirror findings by Wagner et al. (2022), who emphasized that low-income and minority families often encounter fragmented care coordination, forcing caregivers into reactive, piecemeal advocacy at high emotional and financial cost. The persistence of these barriers suggests that narrowing the gap between legal entitlements and actual access will require more than minor tweaks; it will necessitate profound, system-level change. This marks the pivot to the next section, transitioning from barriers to strategies. Theme three explores how families cultivate empowerment, refine their advocacy skills, and mobilize resources to challenge the systems that constrain them.

Empowerment Process and Advocacy Behaviors

Empowerment theory offers a lens for understanding advocacy behaviors in special education. Zimmerman's (1995) framework, linking intrapersonal (self-

confidence), interactional (system navigation), and behavioral (action-taking) empowerment, resonates strongly in special education contexts. Pearson and Meadan (2021) demonstrated that targeted training in IDEA procedures, rights-based language, and collaborative communication significantly boosted caregivers' intrapersonal and interactional empowerment. Parents felt more competent and engaged, and they were able to participate more effectively in IEP meetings, often shifting school responses from perfunctory compliance to genuine collaboration. Similarly, Petri et al. (2020) found that when parents understood the "why" behind educational policies and procedural safeguards, they became more strategic in their advocacy, using data, precedent, and explicit language to press for services. Holcomb-McCoy and Bryan (2010) argued that such empowerment requires consultants and educators to intentionally reduce professional dominance in decision-making, positioning caregivers as legitimate partners. Without this structural and relational shift, even the most knowledgeable caregivers risk being sidelined in the processes intended to protect their children's rights.

Research consistently shows that empowerment is shaped not only by individual capacity but also by environmental supports. Foster-Fishman et al. (1998) highlighted how contextual conditions influenced advocacy. Burke et al. (2022) reinforced this by showing that caregivers' advocacy success often hinged on whether schools provided timely information, accessible documentation, and meaningful opportunities for input, factors frequently missing in under-resourced or high-turnover districts. Mann and Gilmore (2023) found that parents who experienced authentic partnership with school staff, characterized by mutual trust, open communication, and shared goal-setting,

reported greater satisfaction and persistence in advocacy, even in challenging contexts. Yet, Harry and Ocasio-Stouten (2021) cautioned that without addressing systemic bias and intersecting inequities, these partnerships risk reproducing privilege, enabling access primarily for families already positioned to navigate institutional systems. This underscores that empowerment is both a product of supportive environments and a challenge to the structural inequities that constrain them.

Parental empowerment also emerges through the interaction of personal and community resources. Itzhaky and Schwartz's (2001) work on parental empowerment highlighted how both individual capacities and community resources interact to sustain long-term engagement in school decision-making, buffer against caregiver burnout, and translate personal efforts into broader systemic change. This emphasis on the reciprocity between personal resources and supportive networks aligns closely with more recent findings by Batz and Blanchard (2025) and Szlamka et al. (2022), who showed that parents embedded in active peer networks, formal advocacy groups, or informal social circles were more likely to persist in advocacy, draw on shared resources, and reinforce their sense of agency in the face of institutional resistance. These networks also provided emotional buffering, reducing burnout and reinforcing caregivers' sense of agency in the face of institutional resistance. Holcomb-McCoy and Bryan (2010) linked this community dimension directly to advocacy skill-building, noting that when caregivers participated in collective spaces that valued their cultural and experiential knowledge, they advanced their children's interests and contributed to shifting professional mindsets toward greater equity and responsiveness. In this way, advocacy becomes more than a

means of securing services; it evolves into a sustained, community-rooted challenge to inequitable systems.

Justification

The literature reviewed thus far demonstrates that while caregivers' legal awareness and empowerment processes have been well-theorized, a significant gap persists in understanding how these concepts interact across varied sociocultural, economic, and institutional contexts. The selection of the core concepts for this study, legal consciousness, empowerment, and advocacy behaviors, reflects both their centrality in prior research and their persistent underdevelopment in integrated frameworks addressing the lived realities of caregivers navigating special education systems. These concepts are particularly salient for examining how policy intent translates, or fails to translate, into equitable educational access under IDEA. Each addressed a distinct layer of engagement: legal consciousness shapes what caregivers know and believe about their rights, empowerment determines their capacity and readiness to act, and advocacy behaviors represent the outward manifestation of that knowledge and capacity in real-world interactions. Studying these together, rather than in isolation, will bridge theoretical insights with the textured realities caregivers face daily.

Existing studies consistently affirmed the relevance of legal consciousness in shaping caregiver engagement. Ewick and Silbey's (1998, 2002) framework has been foundational, outlining how individuals situate themselves with regard to the law through experiences of "before," "with," and "against" the law. However, much of the empirical work has examined this framework in ways that underplay relational, emotional, and

structural barriers. More recent studies by Pearson and Meadan (2021) and Petri et al. (2020) demonstrated that culturally responsive training and community-based legal education can significantly enhance caregivers' ability to recognize and assert their rights. Still, these interventions often occur in isolation, disconnected from broader empowerment models that could amplify their long-term effects. Szlamka et al. (2022) further highlighted how social support networks sustain advocacy over time. Still, such work rarely integrates these relational supports with analyses of systemic inequities that limit access to them. By positioning legal consciousness as a socially embedded, evolving practice rather than a static awareness, this study directly addressed the gap between knowing the law and being able to act upon it in unequal systems.

Empowerment theory provides the second key lens, offering a multidimensional framework for understanding advocacy as both process and outcome. Zimmerman's (1995) tripartite model of intrapersonal, interactional, and behavioral empowerment remains a cornerstone, and Foster-Fishman et al. (1998) expand on it by specifying the structural conditions that foster empowerment: belief in one's efficacy, access to knowledge and skills, opportunities to participate in decision-making, and equitable access to resources. However, more recent research revealed especially relevant dimensions in special education contexts. Burke et al. (2022) demonstrated that empowerment is contingent upon caregivers' capacities and the institutional willingness to share decision-making authority. Harry and Ocasio-Stouten (2021) document how systemic biases and deficit-based assumptions constrain empowerment opportunities for culturally and linguistically diverse families, even when formal legal rights existed.

Itzhaky and Schwartz (2001) demonstrate that parents' empowerment is shaped by both personal resources and supportive community contexts, with opportunities for skill-building and collective problem-solving playing a central role. Together, these findings highlighted a crucial insight that underlies this study: empowerment is co-constructed between caregivers and the systems they engage with, and its sustainability depends on an institutional climate, equitable resource distribution, and culturally attuned engagement strategies.

Advocacy behaviors represent the most visible expression of caregivers' legal consciousness and empowerment, yet they remain underexamined as dynamic, context-dependent practices. Holcomb-McCoy and Bryan (2010) emphasized that effective advocacy often requires translation across professional, cultural, and legal domains, a skill that is unevenly distributed among caregivers due to disparities in education, resources, and institutional trust. Batz and Blanchard (2025) demonstrated that advocacy behaviors are often adaptive, shifting in response to explicit policy barriers and more subtle forms of cultural resistance. A pattern emerged when paired with earlier work by Lalvani (2012) and Trainor (2010a): advocacy is not a singular act but an evolving repertoire shaped by accumulated experiences, emotional labor, and shifting relationships with schools. However, the literature treats these behaviors as isolated events rather than situating them within the legal knowledge and empowerment processes that precede and sustain them. This study responded to that oversight by examining advocacy behaviors as integral to the broader ecology of caregiver engagement, capturing the iterative interplay between knowing, feeling capable, and acting.

Synthesizing across these three conceptual domains revealed a clear rationale for the study's design and research questions. Investigating the intersection of legal consciousness, empowerment, and advocacy behaviors enabled a more comprehensive understanding of caregiver engagement in special education, particularly for those navigating systemic inequities. Moreover, adopting an interpretive approach informed by phenomenology ensured that this study centered on caregiver narratives, capturing the nuances, contradictions, and resilience often absent from purely quantitative accounts. In doing so, it responded directly to calls in the literature (Harry & Ocasio-Stouten, 2021; Pearson & Meadan, 2021) for research that attends to the interplay between systemic constraints and caregiver agency, an approach that promises both theoretical advancement and practical guidance for fostering equitable, collaborative educational environments.

Summary and Conclusions

The literature review has illuminated three interrelated yet distinct domains that shape caregiver engagement in special education: legal consciousness, empowerment, and advocacy behaviors. Across decades of literature, these concepts have been demonstrated to operate as individual capacities and relational, systemic constructs that are shaped by context. Legal consciousness provided the foundation for caregivers' understanding of their rights, their interpretation of those rights, and how institutions enact or constrain those understandings. Empowerment theory was able to build upon that foundation, encompassing both the personal sense of agency and the structural conditions that enabled meaningful participation. Advocacy behaviors served as the

outward expression of these capacities, translating knowledge and empowerment into action within the complex ecology of special education systems.

What is known from the literature is that each of these domains has been studied in depth, but often in isolation. Legal consciousness research has established strong theoretical frameworks (Ewick & Silbey, 1998, 2002) and documented interventions that improve rights awareness. However, there remains a limited synthesis of how such awareness functions alongside emotional resilience, relational trust, and systemic accessibility. Empowerment studies have traced the interplay between personal efficacy and structural supports, but fewer have explicitly linked empowerment outcomes to the sustained advocacy behaviors necessary for navigating IDEA-mandated processes. Research on advocacy behaviors has richly described caregivers' actions, from attending IEP meetings to mobilizing community networks, but often stops short of situating those actions within a broader, integrated model of engagement.

What is less understood, and therefore underrepresented in the literature, is how these three concepts intersect in the lived experiences of caregivers, particularly those from marginalized or under-resourced communities. There is a gap in research that explicitly examines how legal knowledge is built and sustained in inequitable systems, how empowerment is nurtured or constrained by institutional climate, and how advocacy evolves in response to cumulative experiences of both support and resistance. Additionally, little empirical work situates these processes within varied cultural and geographic contexts, despite evidence that such contexts profoundly shape both opportunities and constraints for caregiver engagement.

The present study addressed this gap by integrating legal consciousness, empowerment theory, and the study of advocacy behaviors into a single analytic framework. In doing so, it offers both a theoretical contribution by weaving together strands of literature that have remained practical by generating insights that can inform culturally responsive and equity-focused approaches to caregiver engagement. This integration is particularly timely, given the ongoing disparities in special education access and outcomes, and the growing recognition that policy mandates alone cannot produce equitable participation without deliberate attention to relational and systemic dynamics.

By centering caregiver narratives and employing an interpretive phenomenological approach, this study provided a nuanced account of how these concepts are experienced, negotiated, and transformed in practice. In turn, it contributed to a more comprehensive understanding of advocacy in special education, providing guidance for educators, policymakers, and community organizations committed to building systems where rights are recognized and actively upheld.

The next chapter outlines the research methodology used to investigate these questions. It details the philosophical underpinnings of the study, the selection of participants, the data collection procedures, and the analytic strategies employed. In connecting the conceptual framework developed in this review to the chosen methodological approach, Chapter Three demonstrates how the study design ensured alignment between research aims and execution, thereby maximizing the potential for credible, meaningful findings.

Chapter 3: Research Method

I aimed to explore lived experiences of caregivers navigating the IDEA for their disabled children, with a particular focus on how their understanding of legal rights shapes advocacy behaviors and influences service access. Guided by legal consciousness and empowerment theories, I aimed to elucidate how they interpreted, internalized, and applied their IDEA knowledge in real-world educational contexts. An IPA design was chosen to center caregivers' voices and to capture nuanced meanings they assign to their interactions with schools, agencies, and policy structures.

This chapter includes the methodological framework that was used to address the research question: What are lived experiences of caregivers navigating IDEA for their disabled children? Chapter 3 includes the research design and rationale, my role as the researcher, and the methodology, including participant selection, instrumentation, and data collection procedures. The data analysis plan is outlined, followed by a discussion of strategies to establish trustworthiness and ethical guidelines that guided the study. The chapter concludes with a summary and transition to presentation of results in Chapter 4.

Research Design and Rationale

This question centered on three interrelated concepts: legal consciousness, or how caregivers perceive and engage with their legal rights; empowerment, which is both a process and outcome that influences advocacy, and advocacy behaviors, in which caregivers secure appropriate services for their children. Each concept was integral to understanding how IDEA policy promises are or are not realized in terms of navigating special education systems.

The phenomenon of interest was the subjective, lived experience of caregivers as they encounter and respond to IDEA-related processes. While IDEA provides procedural safeguards and substantive rights intended to guarantee equitable educational opportunities, research shows that many caregivers, particularly those from marginalized communities, are unaware of these protections or uncertain how to use them effectively (Mann & Gilmore, 2023; Rossetti et al., 2021). This lack of awareness hindered advocacy efforts, exacerbated systemic inequities, and ultimately affected children's educational outcomes and development (Burke et al., 2022; Szlamka et al., 2022).

Given this focus on subjective meaning-making, the study was grounded in the qualitative research tradition and employs an interpretative phenomenological analysis (IPA) design (Smith & Nizza, 2022). IPA was well-suited for examining how individuals interpret and ascribe meaning to significant life experiences, emphasizing both shared and idiosyncratic perspectives. It also aligned closely with this study's theoretical framing: legal consciousness theory (Ewick & Silbey, 1998) underscored how people constructed legal meaning through everyday experiences, while empowerment theory illuminates the processes by which individuals gain confidence, skills, and agency in navigating systems. IPA's idiographic approach ensured that the nuanced interplay between these frameworks and participants' lived realities was fully explored.

Alternative qualitative designs, such as narrative inquiry, ethnography, or case studies, were considered but deemed less suitable for the study's aims. Narrative inquiry primarily focused on the structure and chronology of stories, rather than on the underlying meaning-making processes, which were central to this study. Ethnography,

while valuable for exploring cultural contexts, typically requires extended immersion in participants' environments and focuses on group-level cultural patterns rather than analyzing individual perspectives in depth. Case study designs often emphasize bounded systems (such as a single school or district), which could unduly limit the variability of experiences captured here. By contrast, IPA offered both depth and flexibility, enabling me to analyze each participant's account in detail while also identifying thematic connections across cases.

Furthermore, IPA's interpretative lens acknowledged the double hermeneutic, whereby participants made sense of their experiences, and I, in turn, made sense of those interpretations (Smith & Nizza, 2022). This was particularly relevant when studying how caregivers navigate IDEA, as their perceptions were shaped by both formal legal frameworks and informal relational dynamics with educators, service providers, and policy systems. The design also supported a focus on the relational, emotional, and systemic barriers to advocacy identified in prior research (Burke et al., 2022; Harry & Ocasio-Stoutenberg, 2021).

The chosen approach aligns directly with the study's purpose: to explore, in depth, the meanings caregivers attach to their IDEA experiences and how these meanings influence their advocacy behaviors and sense of empowerment. Through IPA, the research aims to generate rich, contextualized insights that are both theoretically informed and practically relevant, addressing the identified gap in the literature and informing more equitable policy and practice in special education.

Role of the Researcher

In this qualitative, phenomenological study, I served as both an observer and a participant. While I am not directly part of participants' lived experiences, I brought professional familiarity with IDEA and related processes, which informed the study's design and my interpretive approach. My primary responsibility as a researcher was to create a space where caregivers could openly share their stories, ensuring that their voices drove the interpretation of the findings rather than my assumptions or prior knowledge. My professional background has provided me with substantial experience in applying IDEA in practice. As an early childhood educator working alongside a special education teacher, I observed firsthand how individualized education programs (IEPs) were developed and implemented. In my current role as a behavioral consultant, I assist individuals with disabilities in managing their behavioral needs. Through that work, I have accompanied clients to IEP meetings, assisting them in navigating procedural steps and advocating for needed supports. These experiences have deepened my understanding of IDEA's intended protections and the systemic barriers that often complicate families' access. However, this insider knowledge also required me to intentionally bracket personal views so that the analysis reflected participants' realities rather than my interpretations.

Although I planned to recruit participants through my company's applied behavior analysis (ABA) network, I did not engage with any current or former clients. My company has a waiver services division, where I work, and a separate ABA division, where recruitment occurred. I had no professional or personal relationships with the ABA

clients, their families, or the registered behavior technicians (RBTs) who provide their services. This structural separation minimized the likelihood of any preexisting familiarity or power differential between potential participants and me.

Given my conviction that systemic barriers to equitable education necessitate urgent attention, I acknowledged the potential for personal bias. I addressed this by practicing reflexivity throughout the research process, while maintaining a journal to document my assumptions, reactions, and evolving perspectives. I also engaged in peer debriefing with colleagues to critically examine my interpretations, ensuring they were grounded in the data rather than preconceived notions about IDEA or special education systems. Ethical safeguards were implemented to protect participants' privacy and autonomy. I have removed any identifying information from transcripts and replaced it with pseudonyms; any potentially revealing contextual details will be generalized. Digital data, including audio recordings and transcripts, is stored on encrypted, password-protected devices accessible only to me. Participation in the study was entirely voluntary, with no incentives offered, and informed consent was obtained from each participant before data collection.

Through this approach, I balanced the strengths of my professional insight with the rigor of a reflexive, participant-centered methodology. By maintaining ethical boundaries, actively managing potential biases, and foregrounding participants' voices, I ensured that the findings authentically reflect the lived experiences of caregivers navigating IDEA.

Methodology

This qualitative study employed an Interpretative Phenomenological Analysis (IPA) design to explore the lived experiences of caregivers navigating the Individuals with Disabilities Education Act (IDEA) for their children with disabilities. IPA was well-suited for this investigation because it emphasized participants' subjective meaning-making, allowing me to interpret those meanings in context (Smith & Nizza, 2022). The approach is grounded in phenomenology's commitment to capturing lived experience, hermeneutics' focus on interpretation, and idiography's attention to detailed, case-by-case analysis. By employing IPA, this study aimed to understand how caregivers perceived their legal rights, interpreted their experiences with special education systems, and integrated these experiences into broader narratives about advocacy and caregiving.

The rationale for IPA aligned directly with the research problem and purpose. While survey-based or experimental approaches measured knowledge of IDEA in the abstract, they did not capture the nuanced interplay of emotions, systemic barriers, and legal awareness that shaped advocacy behavior. IPA, with its emphasis on rich narrative accounts and interpretative depth, provided the best fit for answering the central research question: *What are the lived experiences of caregivers navigating the Individuals with Disability Education Act for their disabled child(ren)?*

Central Phenomenon

The central phenomenon under investigation was caregivers' lived experience of understanding and navigating IDEA, particularly regarding their legal consciousness and empowerment in advocating for their children. This included:

How caregivers interpreted and internalized IDEA's procedural safeguards and entitlements.

How they encountered informational, emotional, and systemic barriers in accessing these rights.

How their perceptions of self-efficacy and institutional support influenced their advocacy behaviors.

Research Setting

The study was conducted with participants recruited (see Appendix A) from the Applied Behavior Analysis (ABA) division of my employer's organization, which operated independently from the researcher's professional role. The ABA side of the company serves families with children who have disabilities. However, it is distinct from the waiver services division where I work, ensuring that there was no prior relationship between the participants and me. Recruitment was extended to professional networks, online caregiver forums, and community-based special education support groups. All interviews were conducted virtually via secure video on Zoom to ensure comfort and confidentiality.

Participants and Sampling Strategy

A purposive sampling strategy was employed to identify 5–10 primary caregivers who met the following inclusion criteria:

Is the primary caregiver (parent, guardian, or relative) of a child aged 3–18 with an active Individualized Education Program (IEP).

Represents a range of IDEA legal knowledge (from limited to extensive).

Willing and able to complete a 30-60-minute interview (virtual or in person)

Recruitment used flyers, email invitations, and social media postings through professional networks, online caregiver forums, and community-based special education support groups.

Data Collection Methods

Data was collected through semi-structured, in-depth interviews lasting 30–60 minutes each. An interview guide (see Appendix C), informed by the study’s theoretical framework (Ewick & Silbey, 1998; Walker et al., 2005), was used to elicit rich, descriptive accounts. Sample question areas included:

Can you tell me more about your understanding of your legal rights under IDEA?

How would you describe your experiences interacting with schools, teachers, and/or special education staff about your child’s services?

What challenges or barriers, if any, have you faced in trying to access the protections and services your child is entitled to under IDEA?

Can you share examples of any strategies you have used to advocate for your child, and how effective you feel they were?

Interviews were audio-recorded (with consent) and transcribed verbatim. Transcripts were de-identified using pseudonyms and stored on encrypted drives accessible only to me.

Data Analysis Procedures

Data analysis followed the six-step IPA process outlined by Smith and Nizza (2022):

Reading and re-reading transcripts for deep familiarity.

Initial note to document descriptive, linguistic, and conceptual comments.

Developing emergent themes from significant statements and phrases.

Searching for connections across themes to create superordinate categories.

Moving to the following case, we will repeat the process while bracketing prior themes.

Looking for patterns across cases to identify shared meanings and unique divergences.

A reflexive journal was maintained throughout the analysis to document the researcher's interpretative decisions and manage potential bias. Member checking was used to confirm that interpretations reflect participants' intended meanings.

Participant Selection Logic

In this study, my target population was primary caregivers of children between the ages of 3 and 18 who currently have an active Individualized Education Program (IEP) under the Individuals with Disabilities Education Act (IDEA). I intentionally narrowed the focus to caregivers actively navigating special education systems because these individuals will most likely have relevant, recent experiences with IDEA's procedural safeguards, entitlement provisions, and advocacy processes.

I used purposive sampling to identify participants who met the study's criteria. This approach was best suited for an interpretative phenomenological analysis (IPA) because IPA emphasizes rich, in-depth accounts from a relatively small, homogenous

group whose experiences are directly tied to the phenomenon under investigation. My criteria for participation was:

The participant was a primary caregiver (parent, legal guardian, or other primary custodian) of a child with a disability.

The child was between 3 and 18 years old and currently has an active IEP under IDEA.

The participant represented a range of IDEA legal knowledge (from limited to extensive).

The participant was willing and able to participate in a 30–60 minute semi-structured interview.

I used a brief screening questionnaire during recruitment to ensure this criterion was met. This confirmed that each participant met the study's age, IEP status, and self-reported range of legal knowledge requirements. I recruited 5–10 participants for this study. This sample size was consistent with IPA guidelines, emphasizing depth over breadth, allowing for detailed, idiographic analysis of each participant's narrative. I aimed for diversity across socioeconomic, cultural, and educational backgrounds to explore a range of perspectives while still maintaining the necessary homogeneity for IPA.

Recruitment occurred through my professional network's ABA therapy branch via social media, which serves children and families I do not know or work with as well. This ensured that I was not recruiting from my caseload or from families with whom I have a direct service relationship, thereby avoiding conflicts of interest or ethical

concerns related to dual relationships. I also distributed recruitment flyers (see Appendix A) via professional networks, online caregiver forums, and community-based special education support groups.

After receiving their expression of interest, I contacted potential participants by email or phone, provided them with a study information sheet, and addressed any questions they had before obtaining informed consent. Regarding saturation, in IPA, the goal is not statistical generalizability but depth of understanding. Data sufficiency was reached when I had conducted enough interviews to capture the nuanced ways caregivers make sense of their IDEA experiences, and when no substantially new themes were emerging from the data. Based on prior IPA studies, I expected this to occur within my planned 5–10 participant range.

Instrumentation

The primary data collection instrument for this study was me, the researcher, consistent with the interpretative phenomenological analysis (IPA) approach. In IPA, the researcher serves as the primary instrument and the interpreter of participants' meaning-making processes (Smith & Nizza, 2022). Semi-structured interviews were my primary tool for gathering rich, detailed participant narratives, as they allowed consistency across cases and the flexibility to pursue unexpected, yet relevant, topics as they emerged. This format was particularly suited for my research question, *What are the lived experiences of caregivers navigating the Individuals with Disability Education Act for their disabled child(ren)?*, because it invited depth, reflection, and personal storytelling. The semi-structured interview protocol (see Appendix C) was developed specifically for this study,

drawing directly from the research question and informed by the conceptual frameworks guiding this work: legal consciousness (Ewick & Silbey, 1998), empowerment theory (Foster-Fishman et al., 1998; Zimmerman, 1995), and advocacy behaviors. This alignment ensured that each question was purposeful and connected to the study's aims.

The protocol was structured into four key sections: rapport-building, core questions on legal consciousness and IDEA, core questions on advocacy and empowerment, and closing reflection. The rapport-building questions were designed to put participants at ease and invite them to begin with familiar, non-threatening topics such as their child's age, grade, and type of services received. In IPA research, the quality of the participant–researcher relationship is critical for eliciting authentic and reflective responses (Smith & Nizza, 2022). Establishing trust early on encouraged participants to share personal stories and emotions that were central to the phenomenological inquiry. These opening moments also allowed me to observe verbal and nonverbal cues, which later added depth to the interpretation of their narratives.

The core legal consciousness section directly addressed participants' understanding of IDEA, how they learned about their rights, and how that knowledge, or lack thereof, has shaped their experiences. These questions were intentionally open-ended, allowing participants to describe not only what they knew, but also how they had come to know it and how they applied that knowledge in their everyday practice. This was essential because, as Ewick and Silbey (1998) demonstrated, legal consciousness was not simply the possession of information but the lived process of making sense of the law within specific relational and institutional contexts. To ensure clarity and avoid

assumptions about legal terminology, I defined specialized terms, such as “IEP” and “procedural safeguards,” in plain language when necessary.

The advocacy and empowerment section moved into action-oriented narratives. Participants were asked to recount specific advocacy experiences and times they felt empowered or powerless. These prompts were informed by Zimmerman’s (1995) empowerment framework, which emphasized intrapersonal (confidence), interactional (understanding systems), and behavioral (taking action) components. Including questions about supports and allies also reflected upon Foster-Fishman et al.’s (1998) structural approach, which underscored the role of environmental conditions in enabling empowerment. I allowed participants to share the “what” of advocacy and the emotional labor, decision-making, and relationships involved in each moment. By grounding these questions in lived examples, I was able to capture the internal and external dimensions of empowerment experienced in special education contexts.

The barriers and supports questions came from literature indicating that caregiver advocacy is shaped by systemic, cultural, and relational dynamics (Harry & Ocasio-Stouten, 2021; Mann & Gilmore, 2023). Asking participants to discuss challenges and how they have tried to overcome them allowed for exploration of both structural barriers and adaptive strategies. This section is particularly valuable for identifying inequities that may not be visible through document analysis or policy review alone and may offer insight into community-based solutions that extend beyond school-based interventions.

The closing section allowed participants to reflect on the entire conversation, share advice for others, and voice any points they felt were not covered. In

phenomenological research, such open-ended closure often yields some of the richest insights, as participants may return to key moments or realizations that arose during the interview itself. This ending also served as a form of debriefing, allowing participants to transition out of the potentially emotional space of the interview while reinforcing that their voices and contributions were valued and appreciated.

The open-ended nature of the questions was intentional. As Smith and Nizza (2022) note, IPA interviews must allow for flexibility, enabling the researcher to follow participants' leads, probe for clarification, and adapt wording to ensure comprehension without introducing bias. I used prompts such as "Can you tell me more about that?" or "What happened next?" to encourage elaboration while maintaining the participant's control over their narrative. Before formal data collection began, I conducted an informal "dry run" of the interview protocol by reading it aloud and reviewing it with a colleague familiar with qualitative interviewing. This allowed me to identify any unclear wording or sequencing issues without requiring formal pilot testing, which is unnecessary for this study.

To maintain accuracy, all interviews were audio-recorded with participant consent and transcribed verbatim. Field notes captured nonverbal cues, contextual details, and immediate impressions that were relevant during analysis. Data will be stored securely on encrypted drives with restricted access to protect confidentiality. Pseudonyms replaced participant names in all transcripts and publications. The interview setting was arranged to maximize privacy, comfort, and accessibility.

The sufficiency of this instrumentation is supported by prior research using semi-structured interviews to explore legal consciousness (Ewick & Silbey, 1998), empowerment (Zimmerman, 1995), and parent advocacy in special education contexts (Burke et al., 2022; Rossetti et al., 2021). These studies demonstrate that such an approach can capture the nuance, complexity, and emotional depth necessary to answer the research question in a phenomenologically faithful manner. My role as interviewer and analyst enables continuity of engagement, central to IPA's idiographic commitment, as I remain closely attuned to each participant's meaning-making while engaging in a layered interpretive process. The design also ensured flexibility for emerging, unanticipated themes, which are critical for advancing understanding in an under-researched area.

Procedures for Recruitment, Participation, and Data Collection

This study collected primary qualitative data through in-depth, semi-structured interviews with caregivers of children with disabilities who have Individualized Education Programs (IEPs) under IDEA. All participants were purposefully selected to ensure they met the established inclusion criteria: (a) they were the primary caregiver of a disabled child between the ages of 3–18, (b) the child currently receives services under an IEP, and (c) the caregiver self-identifies as having a range of legal knowledge of IDEA rights (from limited to extensive). This targeted approach ensured that the data gathered would directly inform the research question regarding the lived experiences of caregivers navigating IDEA. All participants provided informed consent prior to participation, as outlined in the consent form (see Appendix B).

Recruitment was conducted through multiple channels to maximize the diversity of participant perspectives, while remaining practical within my scope and timeframe. I collaborated with my company's Applied Behavior Analysis (ABA) division to distribute recruitment flyers to families I do not personally know through the company's social media platforms, thus avoiding conflicts of interest. Additional outreach efforts were made via professional networks, online caregiver forums, and community-based special education support groups. Online posts included a brief study description, participation criteria, and my contact information, allowing interested individuals to reach out directly. This approach also helped preserve confidentiality, as initial inquiries will come from the participant's initiative.

Once potential participants expressed interest, I conducted an eligibility screening via email or phone to confirm they met the inclusion criteria. This step ensured the sample remained aligned with the study's purpose while preventing participation from individuals with potential conflicts of interest (e.g., current clients). Eligible participants received a formal informed consent form via email, outlining the purpose of the study, the voluntary nature of participation, confidentiality protections, and their right to withdraw at any time without penalty. Only after receiving signed consent did I schedule the interview.

Data collection was conducted through one-on-one, semi-structured interviews that lasted approximately 45–60 minutes. Participants met virtually via a secure Zoom link to accommodate accessibility needs and personal preferences. I personally conducted all interviews to maintain consistency in data collection. The semi-structured format,

guided by my researcher-developed interview protocol (Appendix C), strikes a balance between covering essential topics, such as legal consciousness, empowerment, and advocacy behaviors, and allowing participants to share unique, unanticipated insights. During each session, I reviewed key consent points verbally and addressed any questions participants had. With permission, interviews were audio-recorded using a secure Zoom recording feature. Audio files were uploaded immediately to a password-protected, encrypted storage drive accessible only to me. Handwritten field notes will supplement recordings to capture contextual observations and preliminary analytical reflections.

The initial recruitment yielded the targeted 5–10 participants; there was no need to expand outreach efforts to include additional regional and national disability advocacy networks, caregiver support groups, and targeted Facebook communities. I also used snowball sampling, inviting current participants to share the study opportunity with others who met the inclusion criteria. Following each interview, I provided a brief verbal debrief, thanking participants and reiterating how their insights would contribute to understanding caregiver experiences under IDEA. No follow-up interviews were planned; however, participants were contacted to clarify statements or provide additional details as needed during the analysis. Upon completing the study, I emailed participants a one-page summary of the findings, which they could opt to receive, thereby further promoting transparency and reciprocity in the research process. These procedures ensured methodological rigor, ethical sensitivity, and alignment with the interpretative phenomenological analysis (IPA) approach, which values rich, detailed accounts of participants' lived experiences. By systematically recruiting, screening, and interviewing

caregivers who met specific, relevant criteria and documenting each step in detail, this study yielded credible, transferable insights into how IDEA is understood, navigated, and acted upon in everyday caregiving contexts.

Data Analysis Plan

This study's central research question was: *What are the lived experiences of caregivers navigating the Individuals with Disability Education Act for their disabled child(ren)?* It required an analytic approach to capture both the nuanced personal meanings and the broader structural influences shaping those experiences. I employed IPA, as described by Smith and Nizza (2022). IPA was well-suited for exploring how individuals made sense of significant life events, with an emphasis on understanding the content and meaning of their accounts. It allowed for an in-depth, idiographic focus while still producing patterns and themes that can inform larger scholarly conversations about caregiver engagement, legal consciousness, and advocacy in special education contexts.

The analysis process began with a verbatim transcription of all interviews. Audio recordings were transcribed by me to ensure accuracy and to deepen my familiarity with the data early in the analytic process. Transcripts will be stored in encrypted, password-protected files, with each participant identified only by a pseudonym. During transcription, I noted nonverbal cues (pauses, laughter, tone shifts) that provided additional interpretive context. These were integrated into the interview field notes, which also captured my immediate reflections and potential connections to existing literature or frameworks.

Once transcriptions were completed, the first stage of IPA, immersive reading and re-reading, involved multiple readings of the transcript to familiarize each participant deeply with their narrative. This stage was not simply about reviewing content; it was about entering the participant's world as much as possible, suspending premature interpretations, and allowing their voices to lead the analysis. Initial notes captured descriptive observations, conceptual reflections, and any emerging interpretive insights, marking sections of the text that stood out as particularly rich or significant.

Next, I engaged in line-by-line coding, assigning concise labels to sections of the text that captured significant concepts, emotions, or actions. Codes were both descriptive (summarizing what was explicitly stated) and interpretive (capturing underlying meaning or significance). Coding remained inductive, allowing patterns to emerge from the participants' own words rather than being imposed by a pre-existing framework. However, as grounded in the literature review, legal consciousness, empowerment, and advocacy behaviors served as sensitizing concepts to guide deeper interpretation. These sensitizing concepts helped ensure that the analysis remained anchored in the study's purpose while leaving room for unexpected findings to surface.

Following initial coding, I moved into theme development. Codes that shared conceptual or experiential similarities were grouped into broader categories, and from these, emergent themes were generated. Multiple data excerpts supported each theme and represented a key dimension of participants' lived experiences. In IPA, theme development is iterative, with constant movement between the data, my interpretive notes, and the emerging thematic structure to ensure alignment with participants'

meanings. I also maintained a visual thematic map to track the relationships between themes and subthemes, revising it as necessary when deeper analysis revealed new connections.

To preserve the idiographic commitment of IPA, I analyzed each case individually before making cross-case comparisons. This ensured that each participant's experience was understood on its own terms before identifying patterns across the dataset. Once individual analyses were completed, I identified convergences (shared experiences or meanings) and divergences (unique or contradictory perspectives) among participants. Both were treated analytically, as IPA recognizes that outlier cases often provide critical insight into the phenomenon under study.

I organized transcripts, codes, and memos. While the interpretive work remained researcher-driven, I facilitated systematic data management, easy retrieval of coded segments, and transparent audit trails. Memos were used throughout the analysis to record my evolving interpretations, questions, and decisions, supporting reflexivity and analytic rigor.

In alignment with IPA's double hermeneutic, I remained reflexively aware of my role in the interpretive process. My professional background in supporting disabled individuals and their families, as well as my prior experiences in educational settings, provides both insight and potential bias. To manage this, I engaged in reflexive journaling after each interview and throughout the analysis, noting where my perspectives may have influenced interpretation and actively seeking alternative explanations grounded in the participants' words. Reflexivity was also supported through

regular peer debriefing sessions with colleagues, allowing for external feedback on coding decisions and thematic interpretations.

The final analysis stage yielded a rich narrative account of each theme, incorporating verbatim participant quotes to illustrate and substantiate the interpretations. These narratives connected individual lived experiences to the broader legal and systemic context of IDEA, showing how personal meaning-making intersects with institutional realities. Themes were presented, alongside discussions on how they expanded, challenged, or confirmed existing literature, ensuring that the findings contribute meaningfully to the scholarly conversation.

Discrepant cases, which involved participants whose experiences or interpretations deviated from the majority, were explicitly addressed in the analysis. Rather than being treated as anomalies, these cases were examined for their insights into variability in caregiver experiences and the potential influence of contextual factors such as cultural background, geographic location, or type of disability. Addressing discrepant cases strengthened the credibility and trustworthiness of the study by ensuring that findings did not oversimplify complex realities. To further enhance rigor, I employed Lincoln and Guba's (1985) trustworthiness criteria: credibility was supported through member checking and prolonged engagement with the data; transferability was facilitated by providing thick, detailed descriptions; dependability was strengthened through maintaining a detailed audit trail of analytic decisions; and confirmability was bolstered through reflexive journaling and peer review. By following these procedures, the data analysis yielded a nuanced, credible, and transferable understanding of caregivers' lived

experiences navigating IDEA. This process addressed the research question while ensuring transparency, methodological rigor, and alignment with the interpretative phenomenological approach. The outcome revealed themes that illuminated both shared and unique aspects of caregiver journeys, thereby contributing to a scholarly understanding and offering practical implications for policy, advocacy, and educational practice.

Issues of Trustworthiness

Credibility

I employed several strategies aligned with interpretative phenomenological analysis (IPA) to ensure the credibility of my findings. I conducted in-depth, semi-structured interviews that lasted 30–60 minutes, allowing participants sufficient time to share their experiences fully. I maintained prolonged engagement with the data through verbatim transcription, repeated readings, and detailed analytic memos. Member checking provided participants with interview summaries to confirm accuracy and clarify meanings. Reflexivity was maintained through journaling before and after each interview to track my assumptions and reactions, ensuring that interpretations remained grounded in the participants' perspectives. Additionally, I substantiated each theme with multiple direct quotes from participants, providing a clear link between the findings and the data.

Transferability

Transferability was supported through a detailed description of both the participants and the contexts in which IDEA navigation occurs. I thoroughly accounted for demographic factors, disability types, school contexts, and geographic regions

represented in the sample while maintaining confidentiality. Purposeful sampling was employed to capture diverse experiences across various cultural, socioeconomic, and educational backgrounds. These details will allow readers to determine which findings can be applied to other contexts or caregiver populations.

Dependability

To ensure dependability, I maintained a comprehensive audit trail that documented all stages of the research process, including recruitment, data collection, coding, and theme development. NVivo software was not used for systematic data management and retrieval, while analytic decisions were recorded in dated memos. Peer debriefing with a qualitative research colleague was an external check on coding accuracy and theme alignment. These strategies ensured that another researcher could follow my process and reach similar conclusions.

Confirmability

Confirmability was addressed through reflexive practice and transparent documentation of decisions made throughout the study. Given my professional background in special education and advocacy, I actively sought to identify and minimize the influence of my perspectives. I kept a reflexive journal to track my assumptions and anchor my interpretations in participants' words, using verbatim quotes. This transparent trail from data to claims helps ensure the analysis reflects caregivers' narratives rather than my preconceptions.

Ethical Procedures

This study complied with Walden University's Institutional Review Board (IRB) requirements and federal and ethical guidelines for human subjects' research. IRB approval #11-03-25-0522123 was obtained prior to the recruitment and data collection activities.

Recruitment and Voluntary Participation

Participants were recruited through my company's ABA social media platforms, snowball sampling, and online caregiver forums. Although recruitment materials were shared through my professional network, I did not include current or former clients to avoid conflicts of interest or power imbalances. All participation was voluntary, with no incentives offered.

Informed Consent

Before interviews, each participant received an informed consent form outlining the purpose of the study, what participation entailed, potential risks and benefits, measures of confidentiality, and the right to withdraw at any time without penalty. Consent was obtained electronically prior to data collection.

Confidentiality and Data Security

Participant confidentiality was maintained through the use of pseudonyms in all transcripts and reports. Any identifying details were removed and generalized in the final write-up. Transcripts, field notes, and audio recordings will be stored on password-protected, encrypted devices accessible only to me as the researcher. All data will be retained for five years, after which it will be securely deleted.

Minimizing Risk

The anticipated risk level for participants was minimal, as the primary focus was on sharing experiences rather than engaging in sensitive or potentially harmful activities. However, given that discussing challenges in navigating IDEA may evoke frustration or emotional responses, participants were reminded that they could skip any question or stop the interview at any time. After each interview, a brief debriefing was conducted, providing participants with supportive resources as needed.

Researcher Role and Bias Management

My professional background in special education and advocacy did not influence my interpretations. To manage potential bias, I relied on open-ended questioning, reflexive journaling, and member checking to ensure participant voices remained central. I also adhered to IPA's idiographic approach, considering each participant's experience before identifying cross-case themes.

Summary

This chapter described how I approached studying the lived experiences of caregivers navigating the Individuals with Disabilities Education Act (IDEA) for their children. I selected a qualitative, phenomenological design to capture the nuanced, personal meanings caregivers attach to advocacy and decision-making. I also outlined the research questions, the theoretical lenses guiding the work, and why Interpretative Phenomenological Analysis (IPA) was the most suitable approach for analyzing these stories. I described how participants were identified through purposive sampling based on clear inclusion criteria, and how semi-structured interviews were used to gather detailed,

first-person accounts. The analysis plan outlined how I transitioned from transcripts to themes, while remaining faithful to participants' words and experiences. I addressed trustworthiness through thick description, member checking, and reflexive practice, and I detailed ethical safeguards, consent, confidentiality, and conflict-of-interest procedures, in line with IRB requirements.

With this methodology, the study aimed to generate meaningful insights into caregivers' legal consciousness, empowerment, and advocacy practices. The intent is for the findings to be both rigorous and helpful in improving policy and practice. Chapter 4 now turns to the results, introducing the participant group and presenting the themes that emerged from their narratives.

Chapter 4: Results

The purpose of this interpretative phenomenological analysis (IPA) study was to explore the lived experiences of caregivers as they navigate the Individuals with Disabilities Education Act (IDEA) for their children with disabilities. Drawing from legal consciousness theory and empowerment theory, the study aimed to understand how caregivers interpret their legal rights, make meaning of institutional interactions, and act within the educational system to advocate for services. The central research question guiding this inquiry was:

What are the lived experiences of caregivers navigating the Individuals with Disabilities Education Act (IDEA) for their disabled child(ren)?

This chapter presents the study's findings, organized around five emergent themes derived from in-depth interviews with participants. Each theme reflects distinct dimensions of how legal knowledge, empowerment, and systemic conditions intersect to shape advocacy behaviors and access to special education services. The chapter begins with a description of the setting and participant demographics, followed by sections detailing data collection, data analysis, and evidence of trustworthiness. The chapter concludes with a presentation of the results, using participant quotes to illustrate each theme.

This chapter centers the voices of caregivers who shared deeply personal and nuanced accounts of their advocacy journeys. Through detailed interviews, participants described navigating procedural safeguards, interpreting legal jargon, attending ARD/IEP meetings, and responding to barriers with varying levels of empowerment and

understanding. Their narratives reveal both the promise and limitations of IDEA when filtered through real-world challenges, such as limited school support, cultural disconnects, and gaps in legal literacy. Consistent with the interpretative phenomenological approach, emphasis is placed on how participants make meaning of their experiences, offering insights not only into what occurred, but how they interpreted and acted upon their legal rights in context. These findings contribute to a deeper understanding of the emotional labor, strategic decision-making, and systemic navigation involved in advocating for children with disabilities.

Setting

This study was conducted with participants located across multiple U.S. states, including Alabama, Louisiana, Texas, Indiana, and Georgia. Participants represented a diverse range of educational and advocacy contexts, reflecting the geographic and systemic variability in how IDEA is implemented and experienced across the country. Notably, one participant highlighted that in Louisiana, only two schools currently offer inclusive education, pointing to significant limitations in service delivery. Two participants were themselves educators, and one worked professionally in a related field, providing them with an insider perspective on both policy and practice. These varying contexts contributed to differences in legal awareness, access to supports, and advocacy strategies. While some participants were able to draw on professional knowledge or network resources, others encountered barriers shaped by limited school offerings or inconsistent district-level support. These differences in settings are critical for interpreting the themes that emerged, as they situate each caregiver's story within the

broader educational and institutional realm. These contextual nuances are essential for understanding how caregivers' advocacy behaviors were shaped not only by their knowledge and empowerment levels, but also by their environment. For example, families in states with more robust inclusion policies had different entry points into the IDEA process compared to those navigating limited or fragmented services. Thus, the physical, institutional, and professional settings served as both enablers and constraints in some caregivers' journeys through special education systems.

Demographics

The participant group for this study consisted of six women, aged 35 to 75. All participants identified as mothers of children with disabilities and met the inclusion criteria of having engaged with the special education system in the United States under the Individuals with Disabilities Education Act (IDEA). Although the sample was not intended to be generalizable, the demographic diversity among the participants allowed for a rich and diverse exploration of lived experiences within this specific population.

Three of the six participants had adopted their children, bringing an additional layer of complexity and insight to the study, particularly around navigating services without the same biological or medical history context often relied upon in special education settings. Furthermore, half of the participants held professional experience in education-related fields. Specifically, three participants had worked in school systems, as teachers, administrators, or support personnel, and one participant was a practicing Board Certified Behavior Analyst (BCBA). This dual perspective, as both parents and

professionals, provided a unique lens through which they interpreted their experiences and the challenges they encountered when advocating for their children.

Participants also represented geographic diversity, residing in various states across the U.S., including both urban and suburban regions. This variation contributed to a broader understanding of how local policies, school district resources, and community supports (or lack thereof) impacted their journeys. Although racial identity was not a specific selection criterion, it is noteworthy that five of the six participants identified as Black women, offering a culturally grounded perspective on navigating systemic inequities within special education.

The combination of adoptive and biological parenthood, professional expertise, varied locations, and broad age range offered a multifaceted foundation for examining the phenomenon of parental advocacy. These factors were important to consider in the interpretative analysis, as they shaped not only how participants experienced IDEA processes, but also how they made meaning of those experiences in their personal, cultural, and professional lives (see Table 1).

Table 1

Participant Demographics: Race/Ethnicity, Parent Type, and IDEA Familiarity

Participant	Race/Ethnicity	Parent Type	IDEA Familiarity
Hope	Caucasian	Biological	SPED Professional (BCBA)
Patience	AA	Biological	Educator

Gracie	AA	Adoptive	Some familiarity (via family)
Victory	AA	Biological	District Administrator
Justice	AA	Adoptive	No SPED background
Faith	AA	Adoptive	No SPED background

Note. This table uses pseudonyms for the women; AA=African American; SPED=Special Education

Data Collection

Data collection for this study followed the procedures outlined in Chapter Three and was conducted over a three-week period. A total of six participants were recruited using purposive sampling techniques. All participants were primary caregivers of children aged 3–18 who currently receive special education services under an active Individualized Education Program (IEP) in accordance with the Individuals with Disabilities Education Act (IDEA). Each participant identified as having a varying degree of knowledge about their legal rights under IDEA, ranging from limited awareness to moderate or extensive familiarity. These participants represented a diverse range of geographic locations across the United States, contributing to a richer understanding of IDEA navigation across differing educational contexts and state-level systems.

All interviews were conducted virtually using Zoom, in line with the flexible data collection plan outlined in Chapter Three. The virtual setting was chosen by the participants themselves, enabling increased accessibility, convenience, and privacy. It also provided a consistent environment for audio recording, minimizing technical difficulties and supporting high-quality transcription. Prior to each interview, participants were reminded of the voluntary nature of the study, their right to withdraw at any point,

that the interview would be recorded, and the confidentiality measures in place. Consent was confirmed both in writing and verbally before the start of each session.

Interviews were semi-structured and lasted between 30 and 60 minutes, depending on the length and depth of participant responses. The interview protocol, developed in alignment with the study's conceptual framework (legal consciousness and empowerment theory), guided the structure of each session while allowing for flexibility in participant storytelling. This approach facilitated both consistency in data collection across participants and openness to emergent themes and unanticipated insights. Rapport-building questions helped establish comfort and trust, and the core interview questions invited detailed reflection on participants' experiences navigating IDEA and advocating for their children.

All interviews were audio-recorded using Zoom's built-in recording feature, with explicit permission from each participant. Following each interview, the recordings were uploaded to a secure, encrypted, password-protected storage system accessible only to the researcher. To ensure accuracy and immersion in the data, I personally transcribed each interview verbatim. This process enabled early engagement with the content and helped identify initial patterns or points of interest, even before formal coding began. Each transcript was carefully reviewed against the audio recording to confirm fidelity and to capture tone, pauses, and emphasis where relevant to meaning.

In addition to transcripts, field notes were maintained throughout the data collection process. During and immediately after each interview, I recorded contextual observations, including participants' tone, affect, or body language, as well as any

reflections, questions, or analytic insights that arose. These memos supported later stages of analysis, particularly in identifying emergent themes and ensuring a reflexive stance was maintained throughout the study. There were no major deviations from the original data collection plan described in Chapter Three. However, one minor variation occurred in that all interviews were ultimately conducted virtually rather than offering a hybrid option of virtual or in-person interviews. This decision was based on participant preference and logistical considerations, including location and availability. The use of Zoom ensured that each participant had a consistent and confidential interview experience, and the quality of data collected was not compromised by the absence of in-person sessions.

No unusual circumstances were encountered during the data collection process. All six interviews were completed as scheduled, with participants expressing appreciation for the opportunity to share their stories. The richness and depth of the narratives collected were sufficient for the goals of interpretative phenomenological analysis (IPA), providing detailed and personal accounts of navigating IDEA and their advocacy efforts. The combination of audio recordings, verbatim transcripts, and field notes provided a comprehensive and trustworthy dataset for analysis, consistent with the qualitative rigor required for IPA methodology.

Data Analysis

Data analysis was conducted using the Interpretative Phenomenological Analysis (IPA) framework, which emphasizes understanding how individuals make sense of their lived experiences (Smith & Nizza, 2022). The process began with verbatim transcription

of all participant interviews, which were recorded via Zoom and lasted between 30 and 60 minutes. Alongside each recording, I took field notes to document contextual observations, nonverbal cues, and immediate reflections, details that would later enrich the interpretive process. After transcription, I engaged in multiple close readings of each transcript. The first reading was used to gain an overall sense of the participant's narrative and tone; subsequent readings focused on content, language, and the meaning-making process. This immersion allowed me to become deeply familiar with each participant's lived experience before introducing any interpretation.

Next, I began the initial noting phase, where I generated descriptive, linguistic, and conceptual comments directly in the margins of the printed transcripts. Descriptive notes focused on what was being said, linguistic notes captured how participants said it (including repetition, metaphors, or emphasis), and conceptual notes reflected on deeper meanings or assumptions that might underlie a given statement. For example, when one participant stated, "Someone handed me a folder, like two inches thick, and just left," (P2) my descriptive note captured the event ("given folder at diagnosis"), the linguistic note highlighted the abrupt phrasing ("just left"), and the conceptual note reflected a possible emotional impact ("felt unsupported/confused"). This method helped preserve the richness of participants' language while beginning to surface potential areas of significance.

From these detailed notes, I developed emergent themes for each transcript. This involved identifying patterns across the initial notes and grouping similar insights into meaningful units. Themes were grounded in the participants' own words and always

linked back to specific excerpts in the transcript. For example, the earlier quote contributed to an emergent theme of “Lack of Guidance at Point of Diagnosis.” Once I had identified emergent themes for each participant, I grouped these into superordinate themes. This process was iterative and recursive; I moved back and forth between the data, initial codes, and developing ideas, refining and rewording themes as needed. I also compared emergent themes across cases to identify points of convergence and divergence. For instance, while several caregivers described a lack of guidance, their responses differed depending on their prior knowledge or access to support networks. These nuances were preserved as either subthemes or distinct divergent findings.

To organize and track this process, I created a Word table that mapped each excerpt to its initial code, emergent theme, and eventual superordinate theme (See Appendix D for the coding table). After completing the initial coding in Word, I printed each table and physically highlighted data by theme to support visual analysis. For example, Theme 1 was highlighted in red, Theme 2 in purple, and so on. This allowed me to quickly see how frequently and consistently certain themes appeared across participants. It also helped me refine theme boundaries and ensure that each theme was well-supported by data. Throughout this process, I remained mindful of the theoretical frameworks that guided the study, including legal consciousness and empowerment theory. While the analysis was inductive, these frameworks served as sensitizing concepts that helped me interpret patterns in the data without forcing them. For example, the theme “The Power of Self-Advocacy and Knowledge” was informed both by participants’ descriptions of navigating the system independently and by empowerment

theory's emphasis on agency and critical awareness. I also gave special attention to discrepant or outlier cases, those that did not align with the dominant themes. These were not excluded but were instead examined for contextual variables, such as the caregiver's professional background or the timing of their child's diagnosis, which may have shaped their unique experience.

All analysis was done manually, without the use of qualitative data analysis software. This allowed me to remain deeply immersed in each participant's story and maintain a close connection to the data. Reflexive journaling was employed throughout the analytic process to mitigate potential bias, particularly since several participants held professional expertise in advocacy or special education. These reflexive notes helped me remain aware of how my own assumptions might influence interpretation, supporting IPA's double hermeneutic process, where participants make sense of their experiences, and the researcher makes sense of that sense-making. The final output of the analysis was a set of superordinate themes that captured both shared and unique elements of each caregiver's journey. These themes, supported by rich and illustrative quotes, are presented in Chapter 4. Together, they reflect the emotional, cognitive, and structural challenges participants encountered while navigating IDEA, as well as the strategies they employed to advocate for their children in the absence of consistent school-based support. A sample of this coding process, including excerpts, initial interpretations, and emergent themes, is provided in Appendix D to illustrate the development and organization of key themes across participants.

Evidence of Trustworthiness

Credibility

To ensure credibility, I employed several strategies throughout the research process. First, I engaged in prolonged interaction with the data, reviewing transcripts multiple times and annotating participant responses to gain a deep understanding of their lived experiences. I used member checking by inviting participants to review summaries of their interview content, ensuring that their voices and meanings were accurately captured. Additionally, I maintained a detailed audit trail of analytical decisions, journaling my thought process throughout the coding and theme development process. These steps helped ensure that the interpretations were grounded in the participants' accounts and not influenced by external bias or assumptions.

Transferability

Transferability was addressed by providing rich, thick descriptions of participant experiences and backgrounds, along with contextual details about their roles, perspectives, and relationships to special education systems. The diversity in participant backgrounds, including adoptive parents, biological caregivers, and professionals in education and behavior analysis, enhances the potential for readers to determine the applicability of the findings to similar caregiving contexts. By sharing direct quotations and layered interpretations, readers will be able to assess the resonance of the findings in relation to other populations or systems.

Dependability

Dependability was supported through consistency in data collection and analysis procedures. All interviews followed a semi-structured format with the same guiding questions, conducted over Zoom and audio recorded to preserve accuracy. I documented the steps taken during data analysis, from initial coding to theme construction, including any shifts in interpretation that emerged through iterative reflection. Peer debriefing with colleagues also served to validate the evolving analytic process. These measures provided a stable, transparent structure that others could follow or replicate.

Confirmability

To establish confirmability, I kept detailed reflexive notes throughout the study to track my positionality, reactions, and decision-making processes. This allowed me to distinguish between participant meaning and my own interpretations. I purposefully centered the participants' voices, ensuring that interpretations were rooted in direct excerpts and narrative patterns. Additionally, the audit trail, including coded transcripts, theme tables, and analytic memos, supports the transparency and traceability of findings back to the raw data, reinforcing that the outcomes were shaped by participant perspectives, rather than researcher bias.

Results

The lived experiences of parents navigating the special education system were organized into five major themes: (1) Navigating IDEA without Guidance, (2) The Power of Self-Advocacy and Knowledge, (3) Barriers within the School System, (4) The Role of External Support Networks, and (5) Preparing Children for Independence. These themes

emerged from detailed analysis of participant interviews and reflect a range of challenges, strategies, and emotional labor experienced throughout their advocacy journeys. Each theme is presented with supporting participant quotes and interpretive commentary that connect to the study's research questions.

Table 2

Categories and Themes

Theme	Categories/Subthemes
1. Navigating IDEA Without Guidance	Learning through trial and error; Lack of school-provided information; Isolation; Reactive vs. proactive learning
2. The Power of Self-Advocacy & Knowledge	Reading IDEA documentation; Asserting legal rights; Advocacy confidence building; Empowerment through experience
3. Barriers within the school system	Unresponsive administrators; Lack of IEP enforcement; Cultural insensitivity; Educator resistance
4. Role of External Support Networks	Peer-to-peer learning; Support from family/friends with SPED experience; Community and advocacy group resources
5. Preparing Children for Independence	Teaching self-advocacy; Encouraging student voice in IEP meetings; Fostering responsibility; Building long-term life skills

Theme 1: Navigating the IDEA without Guidance

This theme captures the confusion and frustration many parents experienced when first entering the special education system. This theme is organized into three subthemes: (1) Overwhelming Legal Jargon, which captures how the dense and inaccessible language of special education processes created barriers to understanding; (2) Lack of Clear Explanation from Professionals, reflecting how minimal guidance or interpretation was

offered during key decision-making moments; and (3) Absence of Knowledge About Legal Entitlements, highlighting how many caregivers were unaware of their rights or how to advocate effectively.

Together, these categories reflect the early informational and emotional challenges parents faced as they entered the system with limited support. Participants described feeling overwhelmed by educational jargon, receiving minimal explanations from professionals, and lacking a clear understanding of their legal rights under the Individuals with Disabilities Education Act (IDEA). Despite IDEA's intent to ensure equitable access to appropriate educational services (Individuals with Disabilities Education Improvement Act of 2004), parents often found themselves navigating complex processes with little to no support.

The disconnect between policy and practice remains a well-documented concern. While IDEA mandates procedural safeguards and family involvement (Yell & Bateman, 2019), implementation gaps persist at the local level (Dragoo, 2018; U.S. Department of Education, 2025). Research shows that families, especially those from historically marginalized communities, frequently encounter systemic barriers when trying to advocate for their children (Shurr et al., 2023). These barriers include inaccessible language, a lack of proactive communication from schools, and unclear pathways for parent participation (UNESCO, 2018).

This theme directly reflects participants' earliest interactions with the system and connects to the research question, "*What are the lived experiences of caregivers navigating IDEA for their disabled child(ren)?*" highlighting how limited guidance from

schools shaped their perceptions and responses. Emerging subthemes include the emotional toll of overwhelming jargon, the lack of clear explanations by professionals, and the absence of knowledge about legal entitlements, all of which contributed to barriers and obstacles during a critical moment in their advocacy journeys.

Victory's experience set the tone for many others, who similarly described feeling overwhelmed, uninformed, or entirely on her own as she navigated the complexities of IDEA without support. She shared, "I am an educator, so I'm somewhat familiar with the system, but the laws change so often... I'm still not very well-versed" (Victory, P4). Even with a professional background in education, she expressed uncertainty navigating IDEA. This highlights how the law's complexity and shifting policies leave even knowledgeable caregivers without clear direction, showing how systemic opacity can affect even "insiders" (P4). She also noted, "If a parent isn't a strong advocate... the child can get lost in the system" (Victory, P4). This emphasizes the personal burden placed on caregivers to become legal experts and relentless advocates simply to access what should be guaranteed by law.

Justice, navigating an unexpected caregiving role, stated: "I didn't know what he needed at first... I had to learn everything, IEP, IDEA, all of it, by myself" (Justice, P5). Her experience of starting from scratch reinforces the notion of informational gaps and emotional strain, especially for adoptive parents who often face added complexity. She also shared, "When he came into my care, I was just told that he was developmentally delayed" (P5). This reflects how diagnoses and legal pathways were either missing or delivered with inadequate guidance, thereby compounding the confusion surrounding

services and rights. Faith expressed her frustration bluntly: “If you don’t know what you’re reading, it doesn’t help. You don’t know what it is. You really don’t know what to do” (Faith, P6). This speaks directly to the alienating nature of legal jargon. When IDEA isn’t communicated in accessible terms, it becomes a gatekeeper rather than a tool for justice.

Patience shared, “My kids have hearing impairments, and I had no one in my family who actually went through this... There was so much that I had to learn... to make sure I was an advocate for them” (Patience, P2). Her story reflects the emotional toll of entering a legal and educational system without context or mentorship. She had to self-educate to meet her child’s needs, a common thread that ran throughout the participant narratives. She also recalled the moment her child received a diagnosis: “Someone came with a huge folder, like 2 inches thick, and just handed it to me and left” (P2). The information dump, absent of any interpretation or support, left her feeling isolated and overwhelmed. She continued, “I didn’t even know the words inside... I had to go search for everything on my own” (P2). Her experience highlights the subtheme of a lack of clear explanations by professionals, a persistent barrier that many families echoed.

Legal language itself often added to the confusion. One mother noted, “The language isn’t black and white, it’s ambiguous. Every child is different” (P2). Others expressed how this lack of specificity hindered their ability to effectively engage in the IEP process. Another participant succinctly stated, “It’s not a level playing field from the beginning” (P4), highlighting the broader systemic inequality that families must navigate when advocating for access.

Theme 2: Power of Self-Advocacy and Knowledge

This theme foregrounds the proactive, strategic, and often emotionally charged efforts parents described as they assumed ownership of their children's educational journeys. It is structured around two interrelated subthemes: (1) Knowledge as Empowerment, which explores how acquiring legal and educational knowledge enabled parents to challenge decisions, direct services, and advocate effectively; and

(2) The Emotional Labor of Advocacy, which illustrates the ongoing, often invisible work involved in advocating, including preparation, persistence, and emotional strain.

These categories reflect both the strategic and affective dimensions of self-advocacy that emerged across participants' narratives. Participants portrayed advocacy not simply as responding to problems but as anticipating, interpreting, and shaping the system through knowledge, intentional action, and resistance. Their stories reflect three interlocking processes: becoming informed about legal rights and educational frameworks, leveraging that knowledge to challenge school decisions and policies, and bearing the emotional labor required to sustain advocacy over time. Research confirms that, beyond mere participation, parent knowledge and empowerment significantly correlate with advocacy behaviors (Li et al., 2024). Moreover, this theme underscores how professional or experiential access to systems can accelerate readiness for advocacy, yet the emotional toll remains substantial.

Hope shared, "I was in the field before I had Minnie... so as soon as she got her diagnosis at only 6 weeks old... I hit the ground running" (Hope, P1). Her professional

background in education and early diagnosis triggered a heightened sense of urgency; she leveraged her prior knowledge and experience to avoid waiting for the system to act. Later, she reflected, “The principal was offended... but I said, being in this position, what you say is on paper... but what I’ve seen out there in the real world...” (P1). This tension between institutional authority and lived-experience knowledge illustrates her refusal to accept surface-level assurances. She added, “It does make me feel a little bit better and like I’m further ahead in the game... because I do know all the things I need to be doing” (P1). For Hope, the acquisition of this knowledge not only offered a practical advantage but also empowered her with a sense of control, contrasting sharply with her parents, who lacked such access. Finally, she recounted, “They wanted to take her from primarily general education to half-time in the special ed secluded room... I had a really big issue with that...” (P1). Her active pushback against a path she deemed isolating underscores how knowledge can prompt strategic resistance rather than passive acceptance.

Patience noted, “I’m also an educator as well, by nature, so I actually was able to navigate some of this stuff, only because I was familiar with some of the practices...” (Patience, P2). Her background provided her with familiarity in schooling practices, although not necessarily with the legal framework, which meant she still had to fill significant gaps. She observed after a meeting, “My daughter came home and said, ‘Mommy, did you know that I’m getting sign language now?’ She had no idea what I was doing behind the scenes” (P2). This quote highlights the hidden emotional work she was advocating for, which was invisible to her child. In a meeting, she recalled saying, “Everybody has a boss. If this is not going to happen, then I’m going to make sure IDEA

and ADA know” (P2). She used legal tools explicitly to hold the system accountable. She then shared, “I pulled up literature and said, ‘This is what is required. If we can’t follow these directions, I’m going to find someone who will” (P2). This final quote demonstrates the depth of her preparation and her refusal to accept anything less than what is required by law.

Gracie and Victory proposed that knowledge serves as the foundation of strategic advocacy. Gracie described: “IEP or ARD that they did, I was given the IDEA package of what my rights are as a parent, and... unlike most people, I sat down and read every page of that” (Gracie, P3). Knowing her legal rights translated into action: “I learned that I had certain rights and what I needed to do to put pressure on them to get what I needed done, which was to put it in writing.” (P3). This sentiment was echoed when she stated, “I held them accountable. If I didn’t hear back, or if they still push back, I’m asking, why? Why are you saying this? I have the right to request this. Why aren’t you doing it?” (P3). Their voices reflect the “rights-aware” parent who moves beyond participation into challenge and accountability, consistent with research that identifies parental advocacy styles as involving persistence, information-gathering, and negotiation (Rehm & Fisher, 2013). Moreover, empowerment theory suggests that gaining knowledge, control, and resources leads to greater agency (Itzhaky & Schwartz, 2001; Perkins & Zimmerman, 1995).

Victory offered further evidence of advocacy as proactive: “There was a lot of jargon, and it was overwhelming... I needed to figure it all out for myself, so I went into education” (Victory, P4). Her choice to gain professional knowledge in response to her

experience demonstrates how some parents transform their role into one of both expert and accelerator. She added, “If I hadn’t had the experience with my older son, I probably wouldn’t have known how to advocate for my younger one” (P4). These reflections reveal the “learning curve” of advocacy and how experience becomes a valuable resource for future endeavors. This mirrors findings that parents often adopt inquiry and learning roles, turning confusion into agency (Conger & Kanungo, 1988; Murray et al., 2013).

Justice and Faith illustrated how advocacy carries not only strategy but emotional labor. Faith said, “I asked him, ‘Do you want to stay?’ He said, ‘Yes, I want to graduate with my peers.’ But if they don’t want him there, it’s discouraging. They’re ostracizing him. He wants to do good and be with his peers, and they’re not letting him” (Faith, P6). The frustration in this quote reflects the parent's fight for her child’s rights and dignity, knowing that advocacy isn’t just about paperwork, but about everyday, visible outcomes. Justice captured the overload with: “They started listening when I brought in his evaluations and progress from private therapy. They weren’t hearing me until I showed them paperwork” (Justice, P5). This scenario reveals how the parent had to gather external evidence to be heard, underscoring the power of knowledge and verification in advocacy roles. The interplay of emotional labor, managing frustration, providing evidence, negotiating systems, and knowledge acquisition is supported by research on the emotional and time-intensive burden of parental advocacy (Harry & Ocasio-Stoutenburg, 2021; Rossetti et al., 2021).

Across these narratives, two major subthemes emerge: Knowledge as Empowerment: Caregivers who understood law, rights, and education systems felt more

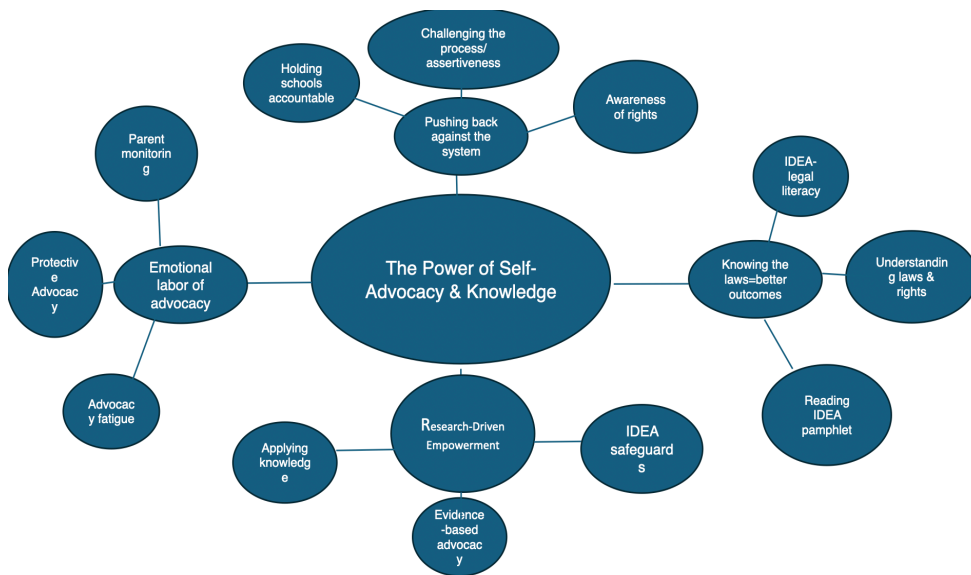
equipped to navigate, challenge, and direct processes. This aligns with empowerment theory's focus on control, competence, and agency (Foster-Fishman et al., 1998). The efforts of self-education, paperwork, negotiation, persistence, and emotional stress were pervasive, reflecting that advocacy is not just informed action but sustained, demanding work. This connects with discussions of the "advocacy expectation" placed on parents of children with disabilities (Rossetti et al., 2021).

In sum, this theme reveals that when parents convert knowledge into action and endure the accompanying emotional work, they position themselves differently in the special education system. They shift from being passive recipients of roles to active drivers of change, though always within a system that still places heavy burdens on them. While knowledge and empowerment equipped many caregivers to challenge the system, these efforts were often met with structural barriers that limited their impact. The next theme examines how school-based obstacles, ranging from under-resourced settings to institutional resistance, further complicate parents' efforts to advocate for their children.

To enhance the clarity and accessibility of the themes, I created visual concept maps to represent how each theme was constructed from participant data. Figure 1 below illustrates the development of the theme "*The Power of Self-Advocacy and Knowledge*", showcasing how individual codes and subthemes clustered together to form a broader understanding of caregiver empowerment. This figure was informed by iterative analysis, participant quotations, and coded excerpts, and it serves as a visual summary of how caregivers' knowledge, experiences, and emotional labor converged to support advocacy efforts. Similar maps were created during the analytical process for all major themes to

support theme development; however, Figure 1 is included here as a representative example.

Figure 1 Power of Self-Advocacy & Knowledge



Theme 3: Barriers within the School System

This theme highlights the numerous structural and interpersonal challenges caregivers faced as they sought to obtain suitable educational support for their children. This theme is organized into three subthemes that illustrate the different layers of institutional challenges parents faced: (1) Resistance from School or District Personnel, which includes opposition to parent requests and adversarial interactions; (2) Inadequate or Inconsistent Supports, showing how service delivery often fell short of what was written in IEPs; and (3) Delayed Action and Limited Accountability, reflecting

participants' experiences with unresponsive systems, staffing shortages, and a lack of follow-through.

These categories reveal how systemic barriers compromised the intent of IDEA and made equitable support difficult to access. Despite the protections and procedural safeguards outlined in IDEA, participants reported that implementation in local school systems frequently fell short, characterized by inconsistent support, resource shortages, and delayed or missing accountability. These barriers undermined advocacy efforts and reinforced the perception that educational equity remains aspirational rather than realized (Fish, 2008; Mann & Gilmore, 2023). Caregivers described three interrelated sub-themes: resistance from schools or districts, inconsistent or inadequate supports, and a lack of timely action coupled with limited accountability.

Patience vividly described the early confusion of navigating available supports: "One of the problems that I had was actually just knowing what services were available... and how to properly advocate for them..." (Patience, P2). The uncertainty and lack of transparent guidance in the early stages set a tone of persistent struggle. She added, "Even the professionals didn't always know what services applied to my child" (P2). This statement highlights how the system's confusion extends beyond families; school staff themselves may lack clarity, placing an additional burden on caregivers to fill the knowledge gaps (Mapp & Kuttner, 2013). Patience further encountered direct resistance even when advocating clearly: "I met with the committee again and said I want to update her communication goals and requested a sign language interpreter. The deaf and hard-of-hearing teacher actually fought me on it. I had to call her out" (Patience, P2).

Her experience illustrates that even informed and engaged parents can face opposition from professionals who perceive the parental role as adversarial rather than collaborative.

Victory's narrative highlights the issue of prioritizing performance over implementation. She shared, "My 16-year-old is in high school ... IEPs are supposed to support the child, [but] the actual resources aren't really there" (Victory, P4). The promise of the IEP framework, intended to guarantee tailored supports, was undermined by her experience of insufficient resources. She reflected, "Teachers and case managers often add things to the IEP that sound good but aren't necessarily implementable. That's discouraging" (P4). This disconnect reflects the findings of Mann et al. (2024), who note that the veneer of inclusion often masks persistent gaps in school capacity and intention. Victory was blunt: "The biggest barrier in navigating IDEA is the lack of resources, financial and human" (Victory, P4). Her comment highlights the systemic under-resourcing of special education systems, a reality that perpetuates inequity rather than mitigates it.

Faith's account underscores the consequences of delayed or absent institutional action. She shared, "Even I tried to call CPS because they're adopted, to see if I could get help. They wouldn't even show up... Right now, he's in a group home... I don't know what else to do" (Faith, P6). Despite extreme behavioral and academic needs, she found herself isolated and unsupported by the system. She also echoed this trajectory with: "The senior is the one I'm constantly fighting for. He's supposed to be leaving, but they're telling me no. I feel like they got him behind because they didn't put things in place" (P6). She further recounted, "I went over the special ed teacher's head to the district

coordinator. He told me they didn't have anybody they could put in place right now, but they're trying to hire. I'm like, 'That's beside the point, he's still failing now'" (P6).

These stories reflect delays in implementation, a lack of staffing, and insufficient accountability, issues that hinder student progress and burden families (Sandoval et al., 2021).

Gracie's experiences added further depth to this theme by illustrating how knowledgeable parents sometimes had to escalate beyond the school level to get results. She shared, "At one point, I had to file with IDEA because something transpired in one of the arts or something, so I had to go above them to get it resolved. As a result, the principal called and said she was sorry that happened..." (Gracie, P3). Her decision to file a formal complaint underscores how parents are sometimes compelled to invoke procedural safeguards when informal channels fail, demonstrating both their agency and the limitations of school-based accountability. She also noted, "I went through IDEA and filed a complaint or challenge, and because I thought that was too severe for him, he'd never had any disciplinary problems or issues in any of the schools he's ever been in..." (P3). This highlights the emotional toll and deliberation required to push back against decisions that feel punitive or misaligned. Gracie's experience revealed a pattern echoed across participant narratives: that meaningful advocacy often requires escalation, documentation, and persistence, even when the issues at hand could have been prevented with better communication or institutional responsiveness.

Justice's experiences further revealed how barriers within the school system are not just about access, but about resistance, delay, and forced persistence. She shared, "I

have a 4-year-old who is autistic, and they denied him for services. They told me he did not need an IEP because he is testing on a first-grade level. So, in my opinion, I'm currently in battle with them" (Justice, P5). This framing of advocacy as a "battle" reflects how schools often use academic benchmarks to dismiss eligibility for support, ignoring the child's broader developmental needs. It also echoes patterns identified by Mann, Kennedy-Wood, and Gilmore (2024), who found that schools often reject services based on narrow, performance-based criteria, rather than holistic assessments of student need.

In another case, Justice described the burden of having to fund external intervention due to institutional neglect personally: "They left him in regular pre-K... then told me he's gonna fail kindergarten. I paid for a tutor, and I bid them to redo his IEP" (Justice, P5). Her frustration encapsulated a common narrative in this study: parents often have to overcompensate for gaps in the system, incurring personal financial and emotional costs. As Pearson and Meadan (2021) noted, systemic inequities disproportionately burden families, forcing them to navigate parallel systems just to ensure baseline support. Eventually, her persistence paid off: "They finally gave him a para. I feel like I had to beat them to get it. And now that he has it, he's doing better. He feels safe" (P5). While this outcome is positive, it highlighted a sobering theme: children often begin to thrive only after sustained and exhausting advocacy efforts. The emotional and logistical labor required to achieve what should be baseline services revealed a systemic dysfunction that places disproportionate responsibility on families.

Taken together, the narratives in this theme highlighted systemic inaction, performative compliance, and strained resources. Barriers within schools are not limited to infrastructure or staffing; they include resistance to collaboration, rigid bureaucracies, and inconsistent implementation of services. As Mapp and Kuttner (2013) argued, genuine partnerships require systems to treat parents not as obstacles but as partners. Nevertheless, for many participants, that ideal remained far from their lived reality. These accounts echoed findings from Mann and Gilmore (2023), who noted that when communication and trust between families and schools break down, families increasingly rely on formal complaint mechanisms, often deepening tensions rather than resolving them collaboratively. When schools are slow to act or default to punitive decisions, the burden shifts to caregivers to resist, correct, and advocate, further underscoring how systemic barriers are not just logistical but deeply emotional and procedural in nature.

Across these narratives, the structural limitations of the school system become a central focus. Caregivers were not merely facing isolated incidents but a pattern of institutional shortcomings: from professionals without adequate knowledge to districts lacking human and financial capacity, to timelines that stretched past children's eligibility windows. These barriers magnify the emotional labor of advocacy and the resource gap between policy intent and service delivery. As Fish (2008) found in his study of IEP meetings, parental perception of support and transparency has a profound influence on satisfaction and engagement. However, participants in this study reported the opposite: resistance and a slow pace. In sum, Theme three revealed that parents navigating IDEA are often contending not only with system complexity but also with institutional inaction.

Their advocacy is undermined by a lack of timely, practical support and meaningful collaboration, transforming what should have been a procedural partnership into a labor-intensive struggle for access, accountability, and just practice. While many parents found themselves fighting against the school system, others found strength and support by building networks outside of it, laying the foundation for the following theme: the role of external support systems.

Theme 4: Role of External Support Systems

Caregivers who struggled to secure adequate support from schools often found strength in external networks. These included family advocates, community-based therapists, special education attorneys, and peer support groups. For many, these external resources not only supplemented what schools failed to provide but also affirmed their advocacy efforts, validated their concerns, and offered strategic guidance. This theme examines how families utilized external support to mitigate isolation, address knowledge gaps, and regain control during periods of system failure.

Subtheme 1: Help from Family & Friends. Several participants described leaning on trusted family members, friends, or mentors, often other parents, to navigate the complexities of IDEA. These informal supports helped interpret paperwork, strategize next steps, and emotionally anchor the caregiver during stressful decision-making processes. Faith (P6) shared the pivotal role of her son's tutor: "I haven't had anyone. The tutor was the only one who helped me. She's been with him since 5th grade. When he starts failing, she goes, 'That's not right. They're doing a lot they shouldn't be doing.' She opened my eyes and told me to look into things. Other than that, I don't have

anybody.” The emotional and practical value of this single external ally illustrates how even one informed advocate can drastically shift a caregiver’s ability to respond to school issues. Justice (P5) similarly emphasized the importance of personal networks: “My cousin—she’s an inclusion teacher and has a neurodivergent child.” This brief yet powerful reference illustrates how even casual connections to informed individuals provided emotional support and valuable insights during challenging moments. Gracie (P3) provided multiple examples of how extended networks functioned as guidance systems: “Well, my daughter, my biological daughter, is over the SELPA program in Southern California... She has been able to help guide me and correct me in some areas, because, see, I would be going off on a tangent...” “I have friends who I’ve reached out to who have either referred me to someone else that I have consulted with to get outside views... I’m grateful that I do have people around me that I can do that with, and they’re not all local. I have a niece in Huntsville, in Alabama, who is a SPED teacher and head of the department... I have a friend who has a daughter that specializes in children with special needs...” These excerpts highlight the layered and diverse support systems that can span professions, locations, and lived experiences, and how they helped families develop a more informed approach to advocacy.

Subtheme 2: Lack of Accountability and Timely Action. When schools fell short, participants often sought external professionals such as therapists, advocates, or legal advisors. These individuals often became central to the child’s progress, and in some cases, were the only source of effective intervention. Their support helped parents reframe their advocacy roles and restore agency. Faith (P6) recalled: “It was his tutor

who actually brought it to my attention. She said, ‘Ms. Faith, you have more rights, and they’re trying to not let you use them.’” This external guidance helped Faith challenge school decisions and recognize the limits placed on her son. She also stated: “They always ask me, ‘What do you think we should do?’ I’m like, ‘I’m not the one with the degrees. I’m just trying to help my child.’” This quote conveys both her vulnerability and the misplaced burden schools placed on her, highlighting the gap that professional advocates or outside experts helped bridge. Justice (P5) expressed frustration with the lack of internal guidance: “The teachers don’t tell you what to put into the IEP to best serve your child. We don’t have advocates in Louisiana either. If you want to advocate, you can pay for an outsourced service to help write the IEP.” The notion that access to essential advocacy knowledge requires payment further reflects inequities in system navigation and underscores the importance of outside professionals for those who can access them. Gracie (P3) summed up the necessity of advocacy allies: “...you have to have somebody in your corner. You either need a parent advocate or child advocate to work with you.”

This emphasis on external expertise reflects how systemic failures prompted caregivers to seek solutions, support, and solidarity from outside sources.

In summary, caregivers in this study often relied on external networks when school systems failed to provide adequate support or information. These support systems, ranging from informal family connections to formal professionals, played a critical role in enhancing caregivers’ ability to interpret policies, challenge decisions, and meet their children’s needs. They filled in the gaps where schools had faltered and empowered

families to reclaim agency during moments of confusion, isolation, or systemic inaction. While some caregivers relied on external support to fill institutional gaps, others encountered internal challenges within their families that significantly shaped their advocacy. The final theme explores how family dynamics, including caregiver identity, trauma histories, and cultural expectations, influenced the way caregivers engaged with schools and fought for services.

Theme 5: Preparing Children for Independence

The final theme highlights how participants redefined their roles as caregivers by intentionally preparing their children to become independent advocates for themselves. Across narratives, this process was more than just a parenting responsibility; it became a transformative journey shaped by advocacy. Caregivers described equipping their children with the mindset, skills, and confidence needed to navigate systems, assert their rights, and take ownership of their futures, often in response to persistent systemic failures. This theme also reveals how advocacy reshaped caregivers' own identities, channeling their experiences into personal empowerment, leadership, or a deeper sense of purpose. Two subthemes reflect these dimensions: (1) Preparing Children for Independence, describing how caregivers taught their children self-advocacy, accountability, and life skills; and (2) A Sense of Purpose or Calling, highlighting how advocacy became a larger mission for many, with ripple effects beyond their immediate families. Together, these categories illustrate that even in the face of adversity, caregivers cultivated long-term strength, both in their children and within themselves.

Patience (P2) described how she deliberately coached her children on their rights and the importance of voicing their needs. “I had my son attend his IEP meeting. I told him, ‘If there’s anything I didn’t say, you need to speak up,’” she shared (P2). She added, “You can do hard things. You need to know how to troubleshoot your own equipment. It’s yours — own it.” This intentional scaffolding of independence extended beyond school meetings to daily functioning. Patience further emphasized, “Ask for captions. Ask for notes. Ask for what you need. I had to teach them that it’s okay to ask.” Her approach not only modeled self-advocacy but also affirmed the value of self-efficacy in managing support needs.

Similarly, Victory (P4) underscored the importance of not using a disability label to excuse a lack of preparedness. “You have to teach your kids independent living skills early... ADHD or not, you still need to teach consequences and responsibility,” she stated (P4). She repeated this belief later, asserting, “I didn’t make excuses. ADHD or not, you still need to teach consequences and responsibility.” These comments reflected her firm stance on accountability and long-term life readiness, regardless of diagnosis. For Justice (P5), fostering independence also involved emotional resilience. After her child lost a long-standing paraprofessional support, she recounted, “He was like, ‘She was my best friend.’ I said, ‘You can do it.’ So every morning, we say affirmations: ‘I’m smart, I’m strong, I’m intelligent, and I can do anything’” (P5). These daily affirmations served as both a coping strategy and a confidence-building ritual, reinforcing her child’s capacity to navigate challenges without relying solely on school personnel.

Across these narratives, it became clear that caregivers were not simply reacting to school failures; they were proactively instilling in their children the tools necessary to survive and succeed beyond the education system. These efforts to foster independence reflect a deep understanding that systemic barriers may persist, but personal empowerment can still be cultivated at home. This theme brings the findings to a close by highlighting how caregiver advocacy extended beyond immediate battles with the system and into long-term preparation for their child's future. The following chapter will discuss the broader implications of these findings, as well as recommendations for policy, practice, and future research.

Chapter 5: Discussion, Conclusions, and Recommendations

This chapter includes a summary of the study's purpose and discussion of key findings. This qualitative research involved exploring lived experiences of caregivers as they navigated the IDEA for their children with disabilities. Guided by the legal consciousness and empowerment theories, I aimed to understand how caregivers interpret, make sense of, and act upon their legal rights as well as examine how varying levels of legal knowledge and empowerment shape advocacy behaviors and influence access to IDEA protections. Using IPA, I addressed their voices to determine how their unique legal understandings impacted their advocacy journeys. Findings revealed both empowering and isolating dimensions of navigating special education systems, with legal literacy, access to support, and systemic barriers emerging as key themes. This chapter includes an interpretation of findings in relation to the existing literature, limitations, and recommendations for practice and future research.

Interpretation of the Findings

This section includes study findings and comparisons to literature as discussed in Chapter 2 via the legal consciousness and empowerment theories. Findings were grounded strictly in data.

Theme One: Navigating the IDEA without Guidance

One of the most prominent findings was caregivers who reported higher levels of legal knowledge, such as knowing IDEA procedural safeguards or how to request evaluations, described more assertive advocacy behaviors. Parental legal awareness enhances access to advocacy and services (Burke et al., 2022; Rossetti et al., 2021). P#

stated, “I held them accountable. If I did not hear back... I have the right to request this. Why aren't you doing it?” This direct invocation of legal rights reflects the choice orientation described by Ewick and Silbey; participants positioned the IDEA as a resource they can use rather than a constraint. Participants who demonstrated intrapersonal self-efficacy described themselves as capable agents of change and used interactional knowledge to engage in behavioral empowerment. Thus, data confirmed and extended existing literature by illustrating how legal knowledge supports progression from awareness to action in real-world settings. However, not all participants who reported awareness achieved successful advocacy outcomes, which diverges from research that treats knowledge as a sufficient condition. Data indicates legal awareness alone does not guarantee service access; systemic context also matters. Empowerment must be supported via institutional responsiveness.

Theme Two: Power of Self-Advocacy & Knowledge

Participants revealed they often internalized systemic failures as personal shortcomings, even when they had a firm grasp of IDEA rights. This emotional burden, frustration, exhaustion, and self-doubt were mainly present in those describing repeated breakdowns in collaboration with schools. P# noted, “knowledge is power. When you don't know your rights, you miss out, and your child suffers for it. I remember beating myself up. I didn't know what he could have.” This reflects the before the law orientation in Ewick and Silbey’s framework, where law is viewed as a remote and authoritative system and not easily accessible or negotiable. This theme confirmed and extended prior findings that emphasized the emotional toll of advocacy. However, it challenged the

assumption that is often implicit with the empowerment theory that knowledge naturally leads to behavioral empowerment. Some participants knew their rights but still felt emotionally paralyzed or overwhelmed. This suggests emotional and relational dimensions of empowerment must be more fully integrated into models of legal consciousness.

Furthermore, Sullivan and Osher (2019) stated the IDEA creates a double bind for marginalized caregivers: they are expected to advocate vigorously yet punished socially or procedurally when they do. This is especially relevant for caregivers of color who face implicit biases that frame their advocacy as antagonism rather than participation (Harry et al., 2005). Findings confirm this phenomenon and suggest emotional labor is not just an individual burden; it is a systemic outcome of inequitable legal implementation.

Theme Three: Barriers within the School System

I also found participants frequently encountered resistance or inaction from schools despite clearly articulating IDEA-based requests. These findings confirmed long-standing concerns in literature regarding implementation gaps between IDEA legal mandates and everyday school practice. P# noted, “They started listening when I brought in his evaluations and progress from private therapy. They weren’t hearing me until I showed them the paperwork.” Yell and Bateman (2019) stated procedural compliance often overshadows substantive outcomes. Families with fewer financial or social resources face greater delays and denials (Liu et al., 2023; Wagner, 2022). When schools delay, ignore, or deflect legal requests, it reshapes caregivers’ sense of legal efficacy,

often moving them from with the law to against the law orientations (Ewick & Silbey, 2002).

Despite possessing procedural knowledge, participants often described repeated institutional barriers, closed-door meetings, confusing communication, and shifting school personnel that rendered IDEA protections ineffective. This supported and extended Burke et al.'s findings on the limits of empowerment when institutional conditions are not conducive. Notably, this study involved addressing personal and relational consequences of such systemic failures.

Theme Four: Role of External Support Systems

While many participants encountered frustration and fatigue, several described developing creative and adaptive strategies to navigate IDEA systems. These strategies included learning legal language, leveraging peer networks, recording IEP meetings, and invoking state-level procedural safeguards. These actions reflected high levels of both interactional and behavioral empowerment, consistent with Zimmerman's model and Foster-Fishman et al.'s evidence that growth in one empowerment domain fuels others.

Notably, many participants shared they did not begin their journeys as confident advocates, but instead grew into them over time, often due to challenging interactions with school personnel. P6 said, "I had to go above them. I finally got the district coordinator to come in and sit in on the ARD, and she told them, 'No, you cannot put him out. No matter how hard you think you can, you can't'." This highlights how confrontation, though emotionally taxing, can catalyze empowerment. Batz and Blanchard (2025) suggested adversity, when coupled with access to peer support

networks, often fosters growth in terms of caregiver advocacy confidence. However, these findings also disconfirmed that empowerment is solely the result of individual effort. P2 noted, “I actually had a parent advocate during my son's time [...] she was the one to actually help me navigate through IDEA, the ADA, and other acts.” This highlighted the importance of relational supports as empowering environments. Szlamka et al. (2022) found that community belonging fosters the sustainability of advocacy. This study extended these insights by demonstrating how empowerment emerges through repeated interplay between caregivers’ legal interpretations, emotional labor, community connections, and system responses. It also illustrated a critical nuance in Ewick and Silbey's framework. Some participants oscillated between the law and anti-law modes, depending on institutional responsiveness, rather than adopting a single, stable orientation.

Theme 5: Preparing Children for Independence

A prominent theme that emerged across caregiver narratives was the intentional effort to equip their children with the skills, mindset, and confidence needed for independence. These parents emphasized the importance of fostering self-advocacy, responsibility, and resilience, often in response to the systemic gaps and limitations they encountered within schools. Patience (P2) described how she deliberately coached her children on their rights and the importance of voicing their needs. “I had my son attend his IEP meeting. I told him, ‘If there’s anything I didn’t say, you need to speak up,’” she shared (P2). She added, “You can do hard things. You need to know how to troubleshoot your own equipment. It’s yours — own it.” This intentional scaffolding of independence

extended beyond school meetings to daily functioning. Patience further emphasized, “Ask for captions. Ask for notes. Ask for what you need. I had to teach them that it’s okay to ask.” Her approach not only modeled self-advocacy but also affirmed the value of self-efficacy in managing support needs. Similarly, Victory (P4) underscored the importance of not using a disability label to excuse a lack of preparedness. “You have to teach your kids independent living skills early... ADHD or not, you still need to teach consequences and responsibility,” she stated (P4). She repeated this belief later, asserting, “I didn’t make excuses. ADHD or not, you still need to teach consequences and responsibility.” These comments reflected her firm stance on accountability and long-term life readiness, regardless of diagnosis. For Justice (P5), fostering independence also involved emotional resilience. After her child lost a long-standing paraprofessional support, she recounted, “He was like, ‘She was my best friend.’ I said, ‘You can do it.’ So every morning, we say affirmations: ‘I’m smart, I’m strong, I’m intelligent, and I can do anything’” (P5). These daily affirmations served as both a coping strategy and a confidence-building ritual, reinforcing her child’s capacity to navigate challenges without relying solely on school personnel.

Across these narratives, it became clear that caregivers were not simply reacting to school failures; they were proactively instilling in their children the tools necessary to survive and succeed beyond the education system. These efforts to foster independence reflect a deep understanding that systemic barriers may persist, but personal empowerment can still be cultivated at home. This theme brings the findings to a close by highlighting how caregiver advocacy extended beyond immediate battles with the system

and into long-term preparation for their child's future. The following chapter will discuss the broader implications of these findings, as well as recommendations for policy, practice, and future research.

Thus, findings affirmed that empowerment is not a linear outcome but rather a fluid process shaped by context, experience, and perceived responsiveness. When schools create spaces for trust, collaboration, and transparent communication, participants reported more sustained and strategic advocacy behaviors. In contrast, when those same systems were dismissive, it forced caregivers into reactive and high-stakes navigation that often intensified emotional stress.

Overall, findings confirmed many insights from prior research, particularly regarding the emotional burden of advocacy, barriers to accessing and applying legal knowledge, and the transformative potential of supportive environments. This study extended the existing knowledge by centering caregiver narratives that revealed how legal consciousness and empowerment evolve dynamically, often shaped more by system responses than by internal beliefs alone. It highlighted that IDEA's procedural protections are necessary but insufficient without equitable implementation, cultural responsiveness, and authentic partnerships between families and schools. This study also advanced both legal consciousness and empowerment theories by emphasizing their interactive, context-dependent nature in the field of special education. By integrating these frameworks, the analysis moved beyond simple measures of legal knowledge or advocacy frequency, instead mapping the emotional, cognitive, and strategic dimensions of real-world legal engagement. These insights contributed to a more holistic and grounded understanding of

how caregivers enact IDEA in daily life, often despite systemic barriers, rather than because of institutional support. The following section examines the study's limitations, including methodological constraints, sample representativeness, and the scope of transferability.

Limitations of the Study

As with all qualitative research, this study included several limitations that influenced trustworthiness and scope of findings. The use of a phenomenological design and purposive sampling of five to 10 caregivers naturally narrowed the breadth of perspectives represented and limited the transferability of insights to broader populations. While this approach allowed for rich, in-depth exploration of lived experiences, it did not aim to generalize findings across all caregivers of children with disabilities navigating the Individuals with Disabilities Education Act (IDEA). Specifically, the study focused on caregivers of children aged 3 to 18 who currently receive services through Individualized Education Programs (IEPs). This excluded families whose children are served under different eligibility criteria, such as Section 504, or who are not yet engaged with the special education system.

The study's dependability was further constrained by its cross-sectional, single-interview format. Because advocacy experiences and perceptions of IDEA may evolve or vary across policy and district contexts, capturing these insights through one-time conversations introduced temporal limitations. Additionally, self-report data introduces potential biases. Caregivers may unintentionally distort memories due to emotional intensity, selective recall, or social desirability. Variability in how participants interpreted

and described key IDEA-related terms may have also impacted the clarity and consistency of the findings. As the sole analyst conducting an IPA, my interpretive lens necessarily influenced the data coding and theme development. Despite my efforts to remain grounded in participants' voices, my theoretical orientation, particularly in relation to legal consciousness and empowerment frameworks, may have influenced how I identified and articulated meaning in the narratives. This potential for researcher bias is an inherent challenge in IPA studies.

To mitigate these limitations and strengthen the study's trustworthiness, I employed several validation strategies. First, I engaged in reflexive journaling and bracketing to actively examine and set aside personal assumptions, maintaining transparency in my interpretive process (Smith & Nizza, 2022). Second, I conducted member checking by sharing early thematic interpretations with participants, allowing them to confirm or challenge my understandings and ensuring greater alignment with their intended meanings (Creswell & Creswell, 2017). Peer debriefing sessions with a fellow researcher provided critical external feedback on theme development and interpretation, helping to challenge overreach and confirm analytical rigor. Additionally, I maintained a comprehensive audit trail that documented all key methodological decisions, ensuring dependability and confirmability of the research process. Finally, through thick, contextualized descriptions of each participant's experience, I aimed to enable readers to assess the potential transferability of the findings to other settings or populations.

Recommendations

Considering the study's findings, several interrelated recommendations emerge that align with its themes, methodological constraints, and the existing literature on caregiver engagement under IDEA. These recommendations are designed to stay within the boundaries of the current research, while drawing on the richly contextualized narratives of caregivers, and to propose actionable areas for future policy, professional practice, and research without extending beyond the data.

The experiences of caregivers in this study highlighted that knowledge of rights under IDEA served as a critical catalyst for advocacy (Burke, Rossetti, & Li, 2022; Rossetti et al., 2021). However, the complexity of the statute and the variability of implementation across districts impose barriers that limit legal consciousness and empowerment among caregivers. To address this gap, policy revisions should include a requirement for states and local educational agencies to produce plain-language summaries of IDEA procedural protections, translated into multiple languages and accessible formats, to enhance comprehension and foster greater interactive empowerment (Ewick & Silbey, 1998; Zimmerman, 1995). Moreover, federal and state agencies should establish enforceable timelines for evaluations, IEP development, and responses to parental requests, which would reduce delays and increase procedural transparency, thereby enhancing caregivers' ability to move from knowledge to behavioral action (Yell & Bateman, 2020). Finally, expanding funding for community-based legal literacy programs, particularly in underserved or rural regions, could enhance caregivers' capacity to navigate the IDEA and reduce disparities in service access (Ahram

et al., 2021). These policy changes align with the empowerment theory's emphasis on interactional (system knowledge) and behavioral (action-taking) dimensions (Foster-Fishman et al., 1998), and they address the study's limitation that caregivers were exclusively from IEP-eligible populations, leaving out those under Section 504 or pre-IEP status.

The study's findings revealed that caregivers frequently encountered educators, particularly general-education teachers and staff, who lacked a comprehensive understanding of IDEA rights, IEP processes, and inclusive pedagogy. This finding aligns with Werner et al.'s (2021) observation that teacher self-efficacy in inclusive settings is highly variable. To foster genuine inclusion and collaborative partnerships with families, teacher preparation programs should require coursework in special education law, inclusive instructional strategies, and culturally responsive family engagement, not only for special education teachers but for all teaching and school leadership candidates. In-service frameworks should also mandate annual school-wide training on IEP development, disability rights, and family advocacy, supplemented by professional learning communities (PLCs) that include general and special educators, administrators, and parent-advocacy representatives. These structures support empowerment by enhancing intrapersonal confidence, knowledge of the interactional system, and behavioral advocacy (Zimmerman, 1995). By broadening educator preparedness, these practices directly address the barrier theme identified in this study, while remaining feasible given the scope of qualitative research in one state or region.

A recurring concern among participants in this study was the opacity of how special-education funds were deployed and whether those resources translated into adequate IEP supports. This aligns with findings by Yell & Bateman (2019) on the disconnect between procedural compliance and substantive educational outcomes. It is recommended that school districts publicly issue annual, detailed reports on the use of IDEA and state-level special-education funding, disaggregated by category (e.g., evaluations, personnel, parent training, service delivery), and match them where possible with student outcome metrics. Additionally, families should be provided with IEP-specific funding summaries in accessible language as part of the IEP review process, thus enabling meaningful participation and enhancing relational trust (Itzhaky & Schwartz, 2001). Finally, state education agencies should increase audits and caregiver feedback loops, with results published to promote accountability and system improvement. These measures are aligned with the empowerment model by affording caregivers greater transparency (interactional domain) and the ability to act (behavioral domain) on resource-use questions. While the current study did not quantitatively track funding flows, its qualitative findings on caregiver perceptions justify further investigation into fiscal transparency and service implementation.

Building on the study's phenomenological insights and acknowledging its limitations (e.g., cross-sectional design, narrow sampling frame), further research is recommended to deepen and broaden the understanding of caregiver advocacy. Longitudinal studies can track how caregivers' legal consciousness and empowerment evolve over time and across critical advocacy events, addressing the limitation of a single

interview snapshot. Additionally, comparative research across eligibility categories (IEP, Section 504, pre-IEP supports) and across diverse demographic settings (rural, multilingual, low-income) would extend the findings to broader populations, thus enhancing transferability (Creswell & Creswell, 2017). Finally, mixed-methods studies combining survey instrumentation with in-depth interviewing could operationalize the mediated model implied by legal consciousness and empowerment theory (Conger & Kanungo, 1988), thereby enabling both breadth and depth of analysis. Given the current study's sample size and qualitative design, these research directions remain within the study's boundary but point future literature toward scalability and generalizability.

Together, these recommendations underscore a holistic approach: strengthening policy clarity, enhancing educator capacity, increasing transparency of resources, and advancing rigorous research. Rooted in caregiver narratives and theoretical frameworks of legal consciousness and empowerment, these recommendations seek to bridge the gap between formal rights and lived advocacy. The following section provides a detailed discussion of the implications for policy, practice, and future research.

Implications

The findings of this study hold significant potential for shaping positive social change at multiple levels: individual, family, organizational, and societal/policy. By centering the lived experiences of caregivers navigating the Individuals with Disabilities Education Act (IDEA), this study suggested tangible pathways for enhancing empowerment, equity, and systemic responsiveness in special education.

Individual and Family

At the individual level, this research underscored the importance of enhancing caregivers' legal literacy and self-efficacy in effectively advocating for their children's rights. Empowerment theory (Zimmerman, 1995) posits that intrapersonal efficacy, knowledge of the interactional system, and behavioral action form a dynamic interplay. The present study extended this model by demonstrating how caregivers' legal consciousness, or their framing of IDEA as either a resource or a barrier, influenced this process. When caregivers understood procedural safeguards and felt more confident to ask for services, they engaged more proactively in IEP meetings, collaborated with schools, and advocated effectively. Consequently, children's access to services improved, which contributed to earlier intervention and better educational outcomes. On a practical level, caregivers may experience reduced stress, increased agency, and more positive relationships with school personnel, transforming what was often described as a reactive, adversarial relationship into one of shared responsibility.

Schools and Educators

For schools, the implications of this study suggested that organizational culture and professional practice must evolve to support genuine inclusion and family-partnered advocacy. The barrier theme revealed in Chapter Four highlighted that even when caregivers possessed legal knowledge, they frequently encountered educators and staff whose training, practices, or attitudes limited meaningful collaboration. By implementing inclusive professional development that emphasizes IDEA rights, IEP processes, and family-school partnerships (Werner et al., 2021), educational institutions can shift from

compliance-driven approaches toward empowerment-oriented practices. When general educators, not just special education teachers, are equipped to view families as partners, the potential for authentic, inclusive learning increases. As schools adopt transparent resource-use practices and foster trust through open communication, the relational gap between families and institutions may narrow, further supporting equitable access and improved outcomes for students with disabilities.

Society and Policy

At the policy level, the findings of this study may help administrators and organizations advocate for systemic shifts that promote equity, transparency, and accountability. The legal consciousness lens (Ewick & Silbey, 1998) suggests that law becomes meaningful only when people can interpret and act upon it in everyday contexts. The recommendations derived from this study, including plain-language summaries of IDEA, enforceable timelines, publicly available funding reports, and inclusive training, offered concrete policy levers that maintain fidelity to the law while enhancing its real-world impact. These reforms can help reduce service inequities rooted in socio-economic, racial/ethnic, and geographic disparities (Ahram et al., 2021; Liu et al., 2023). For instance, when special education funding is disaggregated and published, families can engage with the data, ask informed questions, and hold systems accountable. This transparency fosters empowerment and promotes a more inclusive educational ecosystem that values both procedural and substantive rights under the IDEA (Yell & Bateman, 2020).

Methodological, Theoretical, and Empirical Implications

Methodologically, this study demonstrates the value of a phenomenological, interpretive approach (Smith & Nizza, 2022) in uncovering nuanced caregiver narratives of legal engagement, providing insights that large-scale quantitative studies often overlook. Empirically, the mediated model of legal consciousness → empowerment → advocacy behavior proposed in Chapter Two is reinforced and refined. Importantly, the study's findings emphasized that empowerment is not a linear process but a dynamic one, and that even well-informed caregivers may stagnate if institutional responsiveness is lacking. Theoretically, the fusion of legal consciousness and empowerment theories provided a robust framework for examining advocacy in special education contexts, suggesting that empowerment must incorporate both relational and structural dimensions beyond individual agency (Foster-Fishman et al., 1998).

Suggestions for Future Research

Future studies could build on this work by employing longitudinal IPA methods to investigate how caregivers' legal consciousness evolves and transforms over time. Exploring how different sociocultural groups interpret and respond to IDEA, especially in relation to systemic trust, resistance, or perceived justice, could further illuminate how legal meaning is constructed in daily life. Such research would extend the theoretical reach of legal consciousness frameworks while preserving the nuanced, experiential insights afforded by IPA.

Implications for Practice

Practically, this research provided several action-oriented implications for practitioners working with families and schools. Parent–school communication strategies should not assume uniform legal knowledge; rather, they should be tailored to build caregivers’ procedural literacy and engagement capacity. School districts might implement “family-legal checklists” that outline rights, timelines, and key questions caregivers can ask at IEP meetings. Advocacy organizations could develop peer-mentor programs that pair veteran caregiver-advocates with families new to IDEA, thereby reinforcing the role of support networks (Batz & Blanchard, 2025). Furthermore, professional learning communities (PLCs) within schools can include family representatives as valued contributors, aligning with empowerment frameworks that emphasize shared power and participation (Itzhaky & Schwartz, 2001).

Equity and Inclusion Focus

This study’s focus on caregivers’ knowledge and empowerment also highlighted issues of equity. Families from marginalized backgrounds often face additional barriers, including cultural, linguistic, or institutional ones, that affect how they perceive and utilize IDEA rights (Harry & Ocasio-Stoutenburg, 2021). By attending to these contexts, the implications for social change include developing culturally responsive legal-literacy programs, ensuring translation and accessible formats, and designing school engagement policies that recognize family expertise and cultural capital. Doing so may help narrow the advocacy and service-access gap experienced by under-resourced communities.

Implications

While the recommendations and implications presented here are drawn from the caregiver narratives in this study, they remain bounded by its scope. The purposive sample, cross-sectional design, and focus on IEP-eligible children limit the broad generalizability. Nevertheless, these implications are grounded in rich qualitative data and serve as practical entry points for change, not broad claims of universality. Practitioners and policymakers should treat these implications as context-sensitive and adapt them to local conditions while maintaining fidelity to the underlying principles of legal literacy, transparency, and empowerment.

Overall, this study provided a roadmap for enhancing advocacy capacity, strengthening partnerships between caregivers and schools, and improving transparency and responsiveness in special education systems. The potential for positive social change is significant when individuals, families, organizations, and policymakers work together to transform rights on paper into meaningful practice.

Conclusion

In this qualitative exploration of caregiver experiences navigating IDEA, the voices of those closest to the journey, parents and guardians, revealed a powerful truth: knowledge alone does not guarantee access, but when paired with relational support, system transparency, and responsive institutions, it becomes advocacy in motion. This study highlighted how caregivers transitioned from uncertainty to agency, how they interpreted legal rights, navigated emotional labor, overcame institutional barriers, and leveraged community networks. The findings call us to rethink special-education systems

not as static structures of compliance, but as dynamic ecosystems that require clarity, partnership, and purpose. If we listen to these caregivers and act accordingly, through clearer policies, inclusive training, transparent resource use, and shared participation, then IDEA's promise can move from paper to practice. At its heart, this study is an invitation: to center caregivers as co-creators of educational equity, and to align rights with real change.

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Research Participants Needed



Study Title: The lived experiences of caregivers navigating IDEA for their disabled child(ren)

Are you the parent or caregiver of a child with a disability?

I am conducting a doctoral research study to better understand caregivers' lived experiences navigating the Individuals with Disabilities Education Act (IDEA).

What's involved?

- A one-time interview (about 30–60 minutes)
- Conducted via Zoom or phone call
- Confidential and voluntary participation

Who can participate?

- Parents or caregivers of children (ages 3-18) with an active IEP
- Represent a range of IDEA knowledge (from limited to extensive)
- Willing and able to complete a one-time interview, 30-60 min in-person or via Zoom
- No current/professional relationship with the researcher

Why participate?

Your story can help improve how caregivers are supported in navigating special education systems.



Contact Information:

Natasha W Holmes

Doctoral Student, Walden University

Email:

natasha.holmes1@waldenu.edu

*Approved by Walden IRB.
Participation is voluntary and confidential.*

Appendix B: Informed Consent Form

You are invited to take part in a research study about caregivers' experiences with the Individuals with Disabilities Education Act (IDEA). This form is part of a process called "informed consent," which ensures you understand the study before deciding whether to take part.

This study seeks 5–10 volunteers who are:

- Primary caregivers (parent, guardian, or relative) of a child aged 3–18 with an active Individualized Education Program (IEP).
- Represent a range of IDEA legal knowledge (from limited to extensive).
- Willing and able to participate in a 30–60-minute semi-structured interview (via Zoom or phone).
- Have no current or prior professional/service relationship with the researcher.

This study is being conducted by a researcher named Natasha Holmes, who is a Doctoral student at Walden University.

Study Purpose:

The purpose of this study is to better understand the lived experiences of caregivers navigating IDEA, with a focus on how their legal knowledge and sense of empowerment shape advocacy behaviors and access to services.

Procedures:

If you agree to participate, you will:

- Take part in a one-time, audio-recorded interview (30–60 minutes).
- Be asked about your experiences navigating IDEA, your knowledge of rights, and your advocacy strategies.
- Optionally, you may request a one-page summary of the study's findings once the research is completed.

Here are some sample questions:

1. How did you first learn about your rights under IDEA?
2. Can you describe a time when you felt empowered or confident advocating for your child?
3. What challenges have you faced in understanding or using IDEA's procedural safeguards?

Voluntary Nature of the Study:

Participation is completely voluntary. You may stop at any time, skip any question, or withdraw without penalty. Deciding not to participate will not affect any services or supports you or your child currently receives.

Risks and Benefits of Being in the study:

Being in this study could involve some emotional discomfort when discussing challenges you have faced while navigating IDEA. You may choose not to answer any question or to stop the interview at any time. The risks are slight. Participants will be informed that they are allowed to withdraw from the study at any time at their discretion. If psychological distress arises, the questioning will stop, and participants will be informed of www.FindTreatment.gov or 1-800-662-HELP (4357).

There are no direct benefits to participants. However, your experiences may help educators, policymakers, and advocacy groups better understand how caregivers are supported (or not) in special education systems.

Compensation:

There is no payment for participating in this study.

Privacy:

The researcher is required to protect your privacy. Your identity will be kept confidential within the limits of the law. The researcher is only allowed to share their identity or contact info as needed with Walden University supervisors (who are also required to protect their privacy) or with authorities if court-ordered (very rare). The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. If the researcher were to share this dataset with another researcher in the future, the dataset would contain no identifiers, so this would not involve another round of obtaining informed consent. Data will be kept secure by saving data on a password-protected, encrypted cloud drive with a password known only to the researcher. Personal identifiers will be removed from any published data, and your name will be replaced with a pseudonym. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You can ask questions of the researcher by phone at 225-250-6344 or by email at natasha.holmes1@waldenu.edu. If you want to talk privately about your rights as a participant or any negative parts of the study, you can call Walden University's Research Participant Advocate at 612-312-1210. Walden University's approval number for this study is 02-04-25-0673968. It expires on February 3, 2026.

You might wish to retain this consent form for your records. You may ask the researcher or Walden University for a copy at any time using the contact info above.

Obtaining Your Consent

If you feel you understand the study and wish to volunteer, please indicate your consent by replying to this email with the words, "I consent."

Appendix C: Interview Protocol

Opening:

“Thank you so much for taking the time to speak with me today. As you know, this study is about caregivers’ experiences navigating the Individuals with Disabilities Education Act (IDEA). I’m really interested in learning how caregivers understand their legal rights, what those rights mean in practice, and how they influence advocacy for their children.

There are no right or wrong answers here; what matters is your experience. Everything you share will remain confidential, and your name will not appear in any reports. I’ll be recording our conversation, with your permission, so I can focus on listening and capture your words accurately.

If at any point you’d like to take a break, skip a question, or stop altogether, that’s completely fine.”

“To start, I’d like to ask you a little bit about yourself and your child, and then we’ll move into your experiences with IDEA and advocacy.”

Interview Questions

1. Can you tell me a little about your child and the kinds of services or supports they currently receive under IDEA?
2. How did you first learn about IDEA and your rights as a caregiver?
3. What has been your experience understanding and using your legal rights under IDEA?
4. Can you describe a time when you felt empowered to advocate for your child in the school system?
5. Can you describe a time when you felt limited, uncertain, or powerless when trying to advocate?
6. What kinds of supports or resources (people, programs, trainings) have helped you the most?
7. What challenges or barriers have made it harder to navigate IDEA?
8. How do you think your level of knowledge about IDEA has shaped your experiences or outcomes?
9. What advice would you give to another caregiver who is just starting to navigate IDEA?
10. Is there anything we haven’t covered today that you’d like to share about your experiences with IDEA?

Closing

“That’s all the questions I have for today. Before we wrap up, is there anything else you’d like to share about your experiences that I didn’t ask?”

I really appreciate you taking the time to share your story. It helps us better understand how IDEA works in real life and how caregivers like you can be better supported. After the study is complete, I’ll provide a short summary of the findings if you’d like a copy. Thank you again for your participation.”

Appendix D: Coding Table

Coding Table: Excerpts, Interpretations, and Emergent Themes

This appendix presents a sample of the analytic process used in this study, illustrating how raw transcript excerpts were coded and interpreted. Each row includes a participant ID, the selected excerpt, an initial interpretation grounded in IPA methods, and the emergent theme derived from cross-case analysis. Pseudonyms were replaced with participant IDs to maintain confidentiality. This table supports the data analysis process described in Chapter 3 and referenced in Chapter 4.

Participant	Excerpt	Initial Interpretation	Emergent Theme
(P1)	“I was in the field before I had Minne... so as soon as she got her diagnosis at only 6 weeks old... I hit the ground running.”	Her professional background influenced her proactive response; she felt a sense of urgency and purpose because of what she knew.	The Power of Self-Advocacy & Knowledge
	“The principal was offended... but I said, being in this position, what you say is on paper... but what I’ve seen out there in the real world...”	Tension between professional knowledge and institutional trust. Her lived experience led her to question school intentions.	The Power of Self-Advocacy & Knowledge Subtheme: Pushing Back on the System
	“It does make me feel a little bit better... and like I’m further ahead in the game... because I do know all the things I need to be doing.”	Despite stress, she finds empowerment in her knowledge — contrasting herself with parents who lack the same access or training.	The Power of Self-Advocacy & Knowledge
(P2)	“When I first got the diagnosis, someone came with a huge folder... and just handed it to me and left.”	She was overwhelmed and unsupported at the moment of diagnosis; info was dumped on her without explanation.	Navigating IDEA Without Guidance; Subtheme: Lack of Knowledge on Legalities

Participant	Excerpt	Initial Interpretation	Emergent Theme
(P3)	“I didn’t even know the words inside... I had to go search for everything on my own.”	She lacked accessible support or translation of resources, forcing her to independently learn complex systems.	Navigating IDEA Without Guidance; Subtheme: Lack of Clear Explanations by Professionals
	“The language isn’t black and white — it’s ambiguous. Every child is different.”	She finds legal language vague and ill-suited to capture her children’s unique needs.	Navigating IDEA Without Guidance; Subtheme: Lack of Clear Explanations by Professionals
	“At one point, I had to file with IDEA because something transpired... so I had to go above them to get it resolved.”	She used formal channels when informal routes failed, demonstrating knowledge of rights and persistence.	Barriers Within the School System
	“I went through IDEA and filed a complaint or challenge... I thought that was too severe for him...”	She filed a formal complaint, showing confidence in her advocacy and awareness of disproportionate discipline.	The Power of Self-Advocacy & Knowledge Barriers Within the School System
(P4)	“If you’re relying solely on the school, your child isn’t getting enough... the school is a complement to what you’re doing, not the sole provider.”	Parents must pursue external support to ensure comprehensive services.	The Role of External Support Networks
	“You have to teach your kids independent living skills early... ADHD or not, you still need to teach consequences and responsibility.”	Emphasizes early preparation and not using disabilities as an excuse to avoid life skill development.	Preparing Children for Independence
	“You have to teach your kids independent living skills early... ADHD or not, you still need to teach consequences and responsibility.” (duplicate circled quote)	Highlights belief in accountability and early independence regardless of diagnosis.	Preparing Children for Independence