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Centering the Voices of Caregivers: Understanding their Experiences within the Child Welfare and Special Education Systems

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Centering the Voices of Caregivers: Understanding their Experiences within the Child Welfare and Special Education Systems

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by

Arturo Chavez

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ABSTRACT OF THE DISSERTATION

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by

Arturo Chavez

Doctor of Education

University of California, Los Angeles, 2023

Professor Ron Avi Astor, Co-Chair

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Navigation of the state and federal child welfare and special education systems in the U.S. presents significant challenges for caregivers, particularly those of children with disabilities. This dissertation explores the experiences of caregivers who were involved in these two systems, discussing the challenges they faced and analyzing the strategies and resources they utilized for effective navigation. The paper’s study included semi-structured interviews, allowing for an in-depth exploration of caregiver perspectives and experiences: emotional challenges such as denial, anger, depression, isolation, stress, and eventual acceptance were prevalent among caregivers, and the lack of support from these two systems’ service providers created multiple barriers for caregivers. Yet, finding reveal that caregivers utilized their skills, expertise, and existing relationships to effectively navigate the complexities of the two systems, illustrating that caregivers possess strong aspirations for their children's futures and demonstrate determination in advocating for their needs within the systems.

The dissertation of Arturo Chavez is approved.

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CHAPTER ONE: INTRODUCTION

Children with disabilities who are part of the Child Welfare System (CWS) represent one of the most marginalized segments of the U.S. population. Extensive research focusing on this specific group has revealed that these children not only face detrimental mental health consequences but also encounter unfavorable academic and post-secondary outcomes (Newman et al., 2009). Moreover, it has been observed that children with disabilities are disproportionately represented within the CWS (Kay, 2019), the underlying reason likely because children with disabilities are 3.4 times more susceptible to experiencing abuse or neglect as compared to their non-disabled peers (Sullivan & Knutson, 2000).

Many children with disabilities are automatically thrust into the special education system (SES) within American public schools, which empirical evidence likewise shows to have a history of causing harm (Dettlaff et al., 2020; Raj, 2016). While it has long documented that the CWS in particular has had a significant impact on the well-being of children within its purview (Hill, 2004; George, 1997), similarly the SES often struggles to adequately support the unique needs of children with disabilities (Raj, 2016). Consequently, children with disabilities in the CWS face obstacles in the realms of both education and child welfare (Flynn & McGregor, 2017; McMillan & Jarvis, 2013).

The purpose of the study underlying this dissertation was to gain a deeper understanding of the caregivers' experiences as they engage in and navigate the CWS and/or the SES. The study examined the barriers caregivers encounter, the strategies they employ to advocate for their children, and the resources they utilize throughout their navigation of these systems. In this paper, the term "caregiver" encompasses individuals who include biological parents, non-biological caregivers, caregivers involved in kinship care, and those participating in foster-to-adopt programs. The terms “caregivers” and “caregiver engagement” are used interchangeably, along with more commonly employed terms such as “parents,” “parent engagement,” and “parent involvement.” Prior literature primarily discusses caregivers’ interactions with SES and/or the CWS in the context of parent involvement and/or engagement.

Statement of the Problem

Background

It is widely recognized that caregiver involvement in the school system positively impacts various academic and social-emotional aspects of a child’s educational experience (Boonk et al., 2018). However, what often receives less attention is the type and extent of involvement which can be influenced by caregiver factors such as socioeconomic status (Tan et al., 2020). Notably, parents of children with disabilities tend to engage with the school system differently when compared to parents of non-disabled children as their involvement primarily revolves around their children’s special education program and individual education plans (IEP) (Burke, 2012). The Individuals with Disabilities Education Improvement Act (IDEA) (U.S. Department of Education., n.d.), passed in 1990 and since multiply reauthorized, mandates that public schools involve parents of children with disabilities as equal partners in the IEP team. However, despite high attendance rates at IEP meetings, parents’ participation in decision-making is often limited (Goldstein et al., 1980).

Caregivers of children with disabilities involved in the CWS have a dual obligation of engaging with the SES, with school system engagement being highly encouraged while the CWS involvement is court mandated. Parent involvement within the CWS accelerates the speed of reunification (Jivanjee, 1999), increases the chances that parents are offered appropriate services

(Jones, 1993), and reduces the odds of receiving future referrals to a child protective agency (Littell, 2001). However, despite these significant advantages, parent engagement continues to be a challenging topic for caregivers of children with disabilities involved in the CWS.

Prior to 2010, state child welfare systems were not obligated to report information regarding disabilities in children or other family members (Lightfoot, 2014). This absence of federal requirements for collecting such data by child welfare agencies has likely contributed to limited research exploring the connections between children with disabilities in the CWS and their outcomes. Similarly, research on children with disabilities in the school system and the impact of parent involvement on student outcomes has also been limited, despite initiatives like California Education Code Sec. 52060 (Public Schools Accountability Act of 1999, 2022) which explicitly designated parent involvement as a state priority.

For parents of children with disabilities, caregiver involvement is often more challenging due to the added stressors associated with their child's disability and a lack of institutional support and services. These caregivers often experience social isolation due to the increased time and financial responsibilities involved in caring for their children. This isolation is exacerbated when parents encounter difficulties accessing support services such as affordable childcare, accessible family activities, and respite care (Rosenau, 2000). Children with disabilities often rely more heavily on their caregivers, which leads to higher rates of abuse incidents (Jones, et al, 2012; Sobsey, 1994). A review investigating the prevalence and risk of violence against children with disabilities found these children were three times more likely to experience abuse or neglect compared to their non-disabled peers (Jones et al., 2012).

The lack of caregiver involvement in the school system is frequently attributed to parenting failures, particularly for parents of Color who face stereotypes of being uninvolved, uninterested, or uncaring (Cooper, 2009). However, it is important to recognize that the dearth of caregiver involvement is rooted in systemic issues. Parents of students impacted by adverse childhood experiences often encounter racism, microaggressions, and stereotypes within the school system, which naturally erode trust and result in low rates of parent involvement (Piper et al., 2021.) Compared to middle-class parents, those from disadvantaged backgrounds have less influence over school decisions (Fine, 1993), this disparity maybe stemming from poor parents typically not receiving the same level of respect as their middle-class counterparts from school officials (Noguera, 2001). These parents often feel excluded from decision-making processes and perceive that their voices are unheard or misunderstood (Piper et al., 2021). The lack of agency experienced by economically disadvantaged parents can also be attributed to their limited social and cultural capital (Noguera, 2001) and the harmful impacts of stereotypes perpetuated by school staff, leading to discrimination and potentially traumatic interactions with social services (Piper et al., 2021).

Extent of the Problem

Children in Child Welfare

Understanding the magnitude of the problem is essential to recognizing the need for caregiver support. Nationwide, there are over 423,000 youth in foster care (Child Welfare Information Gateway [CWIG], 2021). In 2019, California had a child population of 9,061,651, with 28,407 children enrolled in the CWS (National Center for Education Statistics [NCES], 2023). Disproportionate representation of Black, Latinx, and Native American children is evident in the child welfare system. In 2019, Black children aged 0-5 accounted for only 5.67% of California's child population but represented 18.46% of the children in CWS foster care. Similarly, Latinx students constituted 46.83% of the child population but comprised 52.6% of the children in foster care. Native American children aged 0-5 constituted 0.47% of the child population but 1.2% of the children in foster care. Conversely, white and Asian children had significantly fewer foster care placements (44% and 1% respectively) compared to their overall population (Child Welfare Information Gateway [CWIG], 2021).

Nationwide, 7.3 million – or 14% – of all public-school students receive special education services under IDEA (NCES, 2023). During the 2018-2019 school year, California schools provided special education services to 795,047 individuals aged 0 to 22 (California Department of Education, 2021). Children with disabilities are prevalent within the CWS and often receive lower-quality services and experience poorer outcomes (Lightfoot, 2014). Typically, these students have teachers who are unprepared to support their unique needs (Forlin, 2001), resulting in less flexibility and lowered expectations (Westwood, 2010). In California, 18% of children in foster care are classified as having a disability, compared to only 7% of all K-12 students (Wiegmann et al., 2014). A report on the risk and prevention of maltreatment of children with disabilities outlined that about one-third of the children in foster care have a disability (CWIG, 2018).

Children with Disabilities

Children with disabilities present unique challenges for their parents and caregivers due to the additional stressors associated with their disabilities and the lack of adequate institutional support and services. These caregivers often experience social isolation as they face increased time and financial responsibilities in caring for their children. These difficulties are compounded when seeking essential support services such as affordable childcare and accessible family activities, and when respite care becomes a struggle (Rosenau, 2000). Moreover, children with disabilities often depend heavily on their caregivers, leading to heightened stress levels for caregivers. Unfortunately, the Covid-19 pandemic exacerbated these challenges and increased the risk of child abuse and neglect in this population (Wu & Xu, 2020). Research reveals alarming rates of psychological aggression during the pandemic, with 80% of children with special needs affected and 20% experiencing episodes of severe physical abuse (Tso et al., 2022). Disturbingly, children with disabilities continue to face a high prevalence of violence, with one-third being survivors of physical, emotional, and sexual abuse (Fang et al., 2022).

In this paper, the term “disability” encompasses a broad range of mental, physical, and other conditions. Specifically, *disabilities* refers to the thirteen IDEA categories: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment (including blindness) (National Dissemination Center for Children with Disabilities, 2012). Among these categories, the most prevalent is specific learning disability, accounting for 33% of students nationwide and 300,395 students in California (California Department of Education, n.d.; NCES, 2023).

Study Overview

Children with disabilities who are involved in both the CWS and SES often experience the poorest educational and mental health outcomes (Newman et al., 2009). However, these two systems often lack effective communication mechanisms, which can lead to unnecessary stress and anxiety for those directly affected (Altshuler, 2003). Studies have shown that approximately 70% of students with learning disabilities experience higher levels of anxiety as compared to their non-learning-disabled peers (Nelson & Harwood, 2011). Furthermore, persistent anxiety has been found to contribute to lower academic achievement, failure to complete high school, and lack of college enrollment (Kessler et al., 1995).

Focusing on the engagement of parents and caregivers in both the CWS and the SES is crucial to bringing numerous benefits to the children involved. Extensive research has demonstrated that parent involvement in their children's school is associated with positive academic outcomes. However, both systems currently fall short in effectively involving and engaging all parents and caregivers, particularly those who have children with disabilities and are also involved in the CWS. The aim of this study was to gain a deeper understanding of the experiences of caregivers who have children with disabilities and had prior CWS and/or SES involvement. The study explored the barriers these caregivers faced, the advocacy strategies they employed, and the resources they utilized as they navigated these two systems. By investigating these aspects, the study identified areas for improvement and potential support mechanisms that could enhance the experiences and outcomes of children with disabilities in these intersecting systems.

Research Questions

The following research questions guided the study:

1) What are the experiences of caregivers navigating the child welfare system and/or the special education system?

2) What sources of support do caregivers utilize when navigating the child welfare system and/or the special education system?

3) What barriers do caregivers navigating the child welfare system and/or the special education system encounter and what advocacy strategies do they use to overcome those barriers, if any?

Study Design

This study utilized qualitative interviews to gain insights into the experiences of caregivers who have navigated both the CWS and SES. The primary goal was to understand their perspectives on engaging and navigating these complex systems. The qualitative interviewing method adopted a comprehensive approach, delving deeply into caregiver experiences, perceptions, and emotions related to parent/caregiver engagement in the educational and child welfare systems.

Study Significance

This study holds significance in broadening the understanding of parental engagement by incorporating the perspectives of various types of caregivers. While there is a substantial body of research on parent engagement, limited research exists on the experiences of non-traditional caregivers in these systems. By addressing this research gap, this study contributes to a deeper understanding of parent and caregiver experiences. Additionally, the study aimed to examine how caregivers navigate multiple systems simultaneously, providing valuable insights into their challenges and strategies.

Conclusion

This dissertation sheds light on the experiences of caregivers who navigate the CWS and/or SES, with a specific focus on those caring for children with disabilities. The research questions explored their experiences, the sources of support they utilized, the barriers they faced, and the advocacy strategies they employed to overcome these barriers. This work holds significance in providing insights into the perspectives of non-traditional caregivers and addressing the research gap in understanding their experiences. By delving deeply into their stories, this paper identifies potential support mechanisms and areas for improvement that enhance the experiences and outcomes of caregivers and their children with disabilities in these intersecting systems.

CHAPTER TWO: LITERATURE REVIEW

Extensive research demonstrates the positive impact of parent involvement in the school system on a child's academic and social-emotional well-being (El Nokali et al., 2010). Similarly, studies indicate that mothers' active engagement in CWS results in improved outcomes in child welfare, family functioning, and maternal mental and physical health, as well as lower levels of alcohol use and child abuse (Dakof et al., 2010).

However, there is limited knowledge regarding the experiences of caregivers involved in both the CWS and SES. This literature review begins with a brief historical overview of the child welfare system and IDEA, then explores the outcomes for students in CWS and SES, with particular attention to special education students within CWS. Subsequently, this chapter examines the benefits of parent involvement within both the CWS and the school system. Additionally, it explores the barriers caregivers face as they navigate the complexities of CWS and SES. Finally, the review concludes with the presentation of the conceptual framework that guided this dissertation.

Over time, the United States has undergone significant changes in its approach to child protection. Myers (2008) identifies three distinct eras that shaped the development of child welfare policies and protections. The first, spanning Colonial Times to 1875, lacked formal protections for children, relying primarily on assistance from relatives, neighbors, and/or, in extreme cases, court intervention. The second era, from 1875 to 1962, witnessed the emergence of non-governmental organizations dedicated to child protection, with the New York Society for the Prevention of Cruelty to Children leading the way. The third era, beginning in 1962 and continuing to the present, marked the growth of government-sponsored child protection initiatives.

The catalyst for U. S. government involvement in child protection occurred with the 1962 publication of the groundbreaking article “The Battered Child Syndrome,” which brought widespread attention to the prevalence of child abuse and neglect (Kempe et al., 1962). This seminal article sparked public and professional discourse on child abuse, leading to amendments to the Social Security Act and the establishment of government-sponsored child welfare services, the availability of which were required in all states by 1975 (Myers, 2008). By the end of 1967, all states had enacted child abuse reporting laws (Myers, 2008).

The process through which children and families become involved with the CWS is defined by the Child Abuse Prevention and Treatment Act Reauthorization (CAPTA) of 2010. CAPTA defines child abuse and neglect as “acts or failures to act by a parent or caregiver that result in death, serious physical or emotional harm, sexual abuse or exploitation, or pose an imminent risk of serious harm.” Each state has its own definitions based on CAPTA. In California, child abuse and neglect is defined under Penal Code Section 273, encompassing various forms of abuse, neglect, and exploitation. Additionally, Penal Code Section 11165.7 mandates that professionals − like teachers or social workers − report suspected child abuse and neglect. Notably, nearly 69% of all reports of child abuse or neglect are made by professionals acting as “mandated reporters” (CWIG, 2021).

In California, county child welfare service systems are responsible for investigating allegations of child abuse and neglect and providing support services to children and families (Legislative Analyst Office, 1996). CWS operates under four main objectives: emergency response, family maintenance, family reunification, and permanent placements. It is crucial to emphasize that parent rights are not automatically terminated solely based on an open Child Protective Services (CPS) investigation, even if the children are placed in out-of-home care.

The 1975 passage of the Education for All Handicapped Children Act marked a significant milestone in advancing the educational rights of students with disabilities. This legislation, later reauthorized as IDEA in 2004, guarantees a “free and appropriate public education” for eligible handicapped children within a “least restrictive environment.” IDEA encompasses 13 distinct disability categories, including autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment (including blindness) (National Dissemination Center for Children with Disabilities, 2012), and mandates the development and implementation of IEPs to ensure the provision of said “free and appropriate” public education for students with disabilities.

Prior to the IDEA, students with disabilities lacked guaranteed educational rights and adequate support. In 1973, approximately one million students were denied public-school education based on their disabilities, while an additional two million students did not receive adequate support aligned with their needs. Since the 1975 implementation of the genesis of IDEA, more than 6.9 million children with disabilities have benefited from special education services in schools (U.S. Department of Education., n.d.) The legislation’s 2004 reauthorization further emphasized the commitment to serving students with disabilities, recognizing disability as a natural part of the human experience and reinforcing the principles of equal opportunity, full participation, independent living, and economic self-sufficiency (Individuals with Disabilities Education Act, 2004).

Despite the progress made by IDEA, students with disabilities still face challenges in accessing a “free and appropriate public education.” McKenna et al. (2019) noted that many of the issues experienced by students with disabilities today echo those of the past. Concerns persist regarding accurate identification of students with disabilities (Morgan et al., 2023), teacher preparation programs and inclusion (Kauffman & Badar, 2016), chronic shortages of qualified special education teachers (Mason-Williams & Gagnon, 2017), and the utilization of inappropriate and pseudoscientific interventions in schools (Travers, 2017). These challenges have a detrimental impact on the mental health and academic outcomes of students with disabilities.

A meta-analysis conducted by Maag and Reid (2006) revealed that students with learning disabilities exhibit higher levels of depression as compared to their non-disabled peers. However, an earlier study by these authors (Maag & Reid, 1994) found that severe symptoms of depression were experienced by just ~2% of students with learning disabilities, consistent with the general population. Brunelle et al. (2019) conducted research on socioeconomically vulnerable students with disabilities and found that 75% of the sample scored higher on measures of anxiety and depression as compared to their non-disabled and affluent peers. Nelson and Harwood (2011) further noted that around 70% of students with learning disabilities experience heightened symptoms of anxiety compared to their non-disabled counterparts which, per earlier studies, (Kessler et al., 1995) adversely affects academic achievement, high school completion, and college enrollment.

Despite the increased inclusion of students with disabilities in mainstream classrooms, they continue to face academic challenges vis-à-vis non-disabled students. Under The Every Student Succeeds Act of 2015, schools are required to track the academic progress of all students in grades 3 through high school (Every Student Succeeds Act, 2015). Lazarus et al. (2016) reported that students with disabilities scored, on average, 38% lower in math and reading as compared to their non-disabled peers. Similarly, a study by Gilmour et al. (2019) found that students with disabilities were, on average, three years behind in reading compared to their non-disabled counterparts.

Among students with disabilities, those with behavioral and emotional disabilities tend to experience some of the most challenging educational outcomes (Knitzer et al., 1990; Wiley et al., 2008). Students classified under the emotional disturbance eligibility category face difficulties in learning, building interpersonal relationships, displaying appropriate behavior and emotions, maintaining a positive mood, and managing physical symptoms or fears (Individuals with Disabilities Education Act, n.d.). As a result, students with emotional disturbance often have lower grades, lower retention rates, and encounter challenges in adulthood (Frank et al., 1995, as cited in Landrum et al., 2003); these challenges tend to worsen over time (Wiley et al., 2008). Approximately 8.1% of the special education population receives services for emotional disturbance (Wagner et al., 2005).

Emotional disturbance is indeed prevalent among children in CWS. A study examining children under the care of social workers found that 72% displayed signs of emotional disturbance (Thompson & Fuhr, 1992). Disturbingly, CWS children with emotional disturbance also experience elevated rates of behavioral and mental health issues (Lee & Johnson-Reid, 2009). Lack of school attendance likewise poses a significant challenge for students with emotional and behavioral disabilities (Landrum et al., 2003); Marder (1992) estimates that up to 56% of students with emotional or behavioral disabilities drop out of school. Research suggests that substantial parenting skills, capacity, and resources are necessary to effectively support the needs of children with serious emotional disturbance (Pickrel, 2002, as cited in Akin et al., 2015). Unfortunately, parents involved in CWS often lack these skills and frequently require support and services themselves. It is evident that CWS children with behavioral and emotional disabilities have high care needs that often cannot be fully met by their parents, who may also require support. Therefore, reimagining parental involvement in both the CWS and the school system is essential to ensure that parents can provide the necessary care and support for their children with disabilities.

Parent Involvement Defined

The definition of “parent involvement” varies across different institutions and individuals, leading to differing interpretations and perspectives, and researchers likewise hold diverse opinions on its meaning and manifestation. Epstein et al. (1997) propose a definition that emphasizes families and communities actively contributing to a nurturing educational environment, encompassing six components: parenting, communication, volunteering, home learning, decision-making, and community collaboration. Green et al. (2007) classify parent involvement into two subtypes: *home-based involvement*, involving activities like assisting with homework and monitoring progress, and *school-based involvement*, including attending conferences and observing classroom activities. Grolnick and Slowiaczek (1994) define parent involvement as parents dedicating resources to their children's academic lives. Hoover-Dempsey and Sandler (1997) suggest that parents’ involvement is influenced by their role perception, confidence in supporting their children’s school success, and the opportunities and invitations for involvement presented by their children and schools. Due to the absence of a standardized definition, parents often face challenges in meeting institution-specific requirements, as each institution outlines its expectations. Furthermore, the broad nature of these definitions presents difficulties for researchers aiming to consistently measure parent involvement (Nye, et al., 2006).

Barriers to Parent Involvement in Schools

Barriers to parent involvement in schools can be understood through the framework of Epstein et al.'s (2002) "overlapping spheres of influence," which examines the intersections of school, family, and community in shaping positive outcomes for children. Building on this framework, Hornby and Lafaele (2011) developed a model to identify barriers to parent involvement, which encompasses parent and family factors, child factors, parent-teacher factors, and societal factors. In the context of parents in CWS with children with disabilities, this model can be utilized to elucidate the specific barriers they encounter.

Parents' Beliefs about Parent Involvement

Parents' attitudes about their involvement are influenced by three central beliefs (Hoover-Dempsey & Sandler, 1997). The first concerns their role in their child's education, which can be shaped by factors such as language barriers, parental experiences in school, and parenting styles and abilities. Studies have shown that parents with lower competence exhibit less warmth, provide fewer problem-solving models, and demonstrate limited interest or confidence in their child's problem-solving abilities (Mondell & Tyler, 1981). This finding is particularly relevant to understanding the barriers faced by mothers with children with disabilities involved in the CWS as they often experience feelings of incompetence that affect their beliefs about their role in their child's education (Mondell & Tyler, 1981).

The second belief pertains to parents' perceived ability to help their children, including their parenting practices. Research has shown that early maternal supportiveness predicts a child's self-regulation and academic achievement, whereas maternal intrusiveness, characterized by autonomy-restriction and controlling behaviors, predicts lower levels of prosocial behavior and academic achievement (Ispa et al., 2004; Liew et al., 2018). Unfortunately, mothers involved in the CWS may exhibit maternal intrusiveness due to abusive or neglectful behaviors, resulting in poor academic, social, emotional, and behavioral outcomes for their children (Egeland et al., 1993).

The third belief centers on parents' perception of their child's intelligence and abilities, which can act as a barrier to parent involvement. Hoover-Dempsey and Sandler (1997) found that parents who believed their child's intelligence and skills were fixed displayed lower levels of parental involvement as they saw little value in becoming highly involved. Research has shown that parents with a *growth mindset*, i.e., believing in the malleability of intelligence, are more engaged in reading and math activities as compared to those with a *fixed mindset* (Mueller et al., 2017). Furthermore, studies exploring the effects of growth mindset on poverty and academic achievement have revealed that students with a growth mindset outperformed their peers with a fixed mindset across all socioeconomic levels (Claro et al., 2016). Therefore, a parent's belief about their child's mindset can impact their involvement, either fostering or hindering their engagement in their child's education (Mueller et al., 2017).

Parents' beliefs about parent involvement greatly helps determine their role in their child's education, their perceived ability to support their child, and their beliefs about their child's intelligence. These beliefs can either facilitate or impede parent involvement in school-related activities.

Socioeconomic Status & Parent Involvement

Parent involvement in schools is directly influenced by socioeconomic status. Research has shown that parent involvement is more effective among individuals with higher socioeconomic status (McNeal, Jr., 2001). The correlation between poverty and special education has also been discussed, with lower-income students having a higher prevalence of disability; however, caution is warranted due to potential systemic biases leading to the over-identification of low-income students in special education (Schifter et al., 2019). A study examining parenting stress in families with children with disabilities revealed that a significant portion of mothers in the sample were not employed, and a substantial proportion earned between $10,000 and $30,000 (Innocenti et al., 1992). Moreover, the research bears out that a parent's household income and education level have a greater impact on parent involvement than do household income and occupation status (Vellymalay, 2012). Similarly, a study focusing on parent involvement found that higher levels of involvement at home were associated with a parent's higher level of education (Al-Matalka, 2014). These findings are noteworthy as many parents involved in the CWS come from low socioeconomic backgrounds and have lower levels of educational attainment (Zilberstein, 2016), further highlighting the challenges of parental involvement for caregivers involved in the CWS who have children with disabilities.

Parent-Child Factors

A child's age can present a barrier to parent involvement, with parents typically being more involved when their child is younger and less involved as they reach secondary school (Hornby & Lafaele, 2011). As children transition from elementary school to junior high, parents often have higher expectations of behavior and responsibility, leading to a decrease in parental involvement (Bryan & Nelson, 1994). However, a study focusing on special education students found that home-based parental involvement increases once a child qualifies for and receives special education services, as mandated by IDEA (Kirksey et al., 2022). Nonetheless, parents of learning-disabled children may participate less in school-based activities due to work commitments and limited free time (Bryan & Nelson, 1995, as cited in Bryan et al., 2001).

A child's disabilities can also act as a barrier to parent involvement, particularly when the child experiences emotional and behavioral challenges. Longitudinal studies have shown that mothers of children with intellectual disabilities face high rates of mental health problems due to their child's behavior problems, with these problems persisting over time (Gray et al., 2011). Mothers of children with autism, Down syndrome, or intellectual disability report higher stress levels when their children exhibit high levels of behavior problems and lack prosocial behavior (Beck et al., 2004). Children with emotional and behavioral disorders may exhibit disruptive and irritating behaviors, leading to negative feelings from others and difficulties in forming relationships with peers and adults (Kauffman, 2001). These behaviors not only hinder the child's success in school but also make it challenging for parents to be actively involved in their child's life.

Parent and family stress associated with a student's disability can also pose a barrier to parent involvement. Parenting a child with disabilities can lead to increased stress levels, isolation, depression, and relationship conflict within the family (Hanson & Hanline, 1990). Parents of children with disabilities generally experience higher stress levels as compared to other parents (Dyson & Fewell, 1989; Innocenti et al., 1992). Longitudinal studies have found a significant relationship between a mother's stress and her parenting experiences, with mothers of children with neurological disabilities reporting the highest levels of stress (Hanson & Hanline, 1990). Caregivers of children and adolescents with autism spectrum disorders have also indicated that behavioral problems contribute the most to stress levels (Lecavalier et al., 2006).

Parent-Teacher Factors

Differences between parents and teachers on various educational factors such as goals, attitudes, and language used, can create potential barriers to parental involvement (Hornby & Lafaele, 2011). Despite the established link between parental involvement and academic success, teachers generally do not receive adequate pre-service training in parent involvement (Hoover-Dempsey et al., 2002). This lack of training may contribute to the divergence of opinions between parents and teachers as this relationship becomes more complex when a child has a disability and thus receives special education services. These parents become equal partners in the IEP team which typically includes special education teachers, general education teachers, service providers, paraprofessionals, and sometimes the student (Lo, 2012). Parents not only have to navigate the multiple services outlined in their child's IEP but also need to collaborate with each teacher and/or support staff involved in delivering those services. Despite the expectation of equal partnership in decision-making, a study examining the experiences of Latino families with their child's special education program found that these parents expressed concerns about insufficient services, faced challenges in effective communication with teachers due to limited English proficiency, and felt disconnected from their children's classroom learning (Hughes et al., 2002).

Societal Factors

Access to schools and education has historically been unequal for people of Color, creating significant barriers to parent involvement. Racial societal factors contribute to this lack of access, leading to systemic disadvantages for families of Color. Black families often face racism when their involvement is assessed based on white family norms, resulting in a deficit perspective that undermines their engagement (Love et al., 2021). In a qualitative study involving parents from migrant backgrounds, compliance and subordination were common responses to the schools' norms, despite feeling worried, uncertain, and frustrated due to a lack of communication (Van Laere et al., 2018). These parents prioritized their child's physical and emotional well-being, a sense of belonging, and participation in the classroom (Van Laere et al., 2018).

While Hornby and Lafaele's (2011) model provides insights into barriers to parent involvement, it does not encompass all influencing factors. Keller and Honig (2004) highlight additional stressors that restrict parental involvement, such as the child's lack of secure attachment relationships, challenging child temperament, parental distress due to role restrictions, poor spousal relationships, and fathers' emotional disengagement. The authors also identify buffering factors that can support parental involvement including marital harmony, implementation of coping strategies by parents, early access to preventative services, continuous support services, collaborative family-school partnerships, available respite care and transportation, and individual support services provided by professionals (Keller & Honig, 2004). These factors play a crucial role in either hindering or facilitating parent involvement beyond what is captured by Hornby and Lafaele's (2011) model.

Models & Theories for Parent Involvement

In the field of parent involvement, researchers have developed various models and theories to understand and promote effective parental engagement. One prominent model is Epstein's (2001) which identifies six components of effective parent involvement: parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community. However, Epstein's model has been criticized for its focus on the school's perspective over the parent's viewpoint (Tekin, 2011).

Another model developed by Hoover-Dempsey and Sandler (1997) foregrounds the parent’s perspective, examining parental involvement through a psychological lens and considering factors such as parental expectations shaped by family, schools, and cultural influences, the parent’s belief in their efficacy to support their child’s success in school, and the perception that the child and school value their involvement.

Other models, such as Sattes’s (1994) three-dimensional framework and Lueders’s (2000) energy-in and energy-out model, provide additional insights into the key components of parent involvement. Christenson and Sheridan (2001) propose four elements to enhance parent involvement: approach, attitudes, atmosphere, and action. Swap (1993) suggests a hierarchy of parent involvement, while Collins (2000) identifies factors such as support, a welcoming atmosphere, appreciation, consideration of parents’ needs, communication, church-school connection, and unifying issues as contributing to successful parental and community involvement.

Researchers also draw on theoretical frameworks to understand parent involvement. Piaget’s (1936) cognitive development theory emphasizes the importance of parent involvement in child development, while Vygotsky’s (1978) sociocultural theory highlights the role of parental engagement in fostering development and academic achievement; Brofenbrenner’s (1979) ecological systems theory underscores the influence of parents as part of a broader system shaping a child’s education (as cited in Tekin, 2011). By exploring these models and theories, researchers gain valuable insights into the multifaceted nature of parent involvement and its impact on children’s educational outcomes.

Barriers to Parent Engagement in the Child Welfare System

Barriers to parent engagement in the CWS are numerous and complex, mirroring the challenges faced in parent involvement within the school system. When parents first come into contact with the CWS, it is often due to allegations of abuse or neglect. The initial visit from a child protection worker can evoke a sense of fear and apprehension among parents who may worry about the potential removal of their children. Studies have long shown that parents experience overwhelming fear during these visits, which can create a barrier to engagement (Diorio, 1992). Conversely, child protection workers have noted that parents' preconceived notions of the CWS's accusatory nature can also impede their ability to engage effectively (Schreiber et al., 2013).

Similar to those in schools, barriers to parent engagement in the CWS are multifaceted. Ferguson (2009) identified several common barriers including parents missing appointments, their inconsistent involvement with support services, the loss of contact with their children, and a resistance to allowing workers into their homes. Assessing child safety becomes more complex when workers assume that a child will be safe solely based on the parent's engagement in services. Conversely, if parents do not engage with services, the risk of harm to the child may increase (Platt, 2012). However, due to heavy caseloads, child protection workers often lack sufficient time to fully assess safety beyond parent engagement. High caseloads also frustrate workers, hindering their ability to build relationships and work effectively with families (Gallagher et al., 2011).

Ethical considerations play a role in hindering parent engagement, especially in cases where parents involuntarily become involved with the CWS due to their child being at risk of harm. Turney (2012) identified three ethical issues – resistance, trust, and the use of power – that can impede effective engagement with parents in these situations. These barriers in parent engagement within the CWS pose significant challenges and should be addressed to better support families and ensure the well-being and safety of children involved.

Intersecting Challenges

The navigation of the CWS and the SES presents complex challenges for parents and caregivers as evidenced by previous research (Dabrowska & Pisula, 2010; Rodriguez-JenKins & Marcenko, 2014). Within the CWS, parents must navigate a network of agencies, policies, and procedures to access the necessary support and services for their children. Similarly, the SES has its own set of regulations, eligibility criteria, and individualized plans that parents must comprehend and engage with to secure appropriate educational support.

Parents and caregivers who have children with disabilities and are involved in both systems encounter additional complexities. They must navigate the intricate intersectionality of these systems, coordinating services and advocating for their children's needs across multiple domains. The lack of coordination and communication between the child welfare and special education systems creates barriers and confusion, impeding parents' access to regular and comprehensive support, consistent with existing literature on system interplay and coordination challenges (Altshuler, 2003). Furthermore, parents and caregivers face the challenges of limited resources, inadequate training and/or knowledge about available services, and comprehending complex legal and educational terminology, as outlined in previous research (Zilberstein, 2016). These factors contribute to caregivers' feelings of being overwhelmed and frustrated by these systems (Benson & Karlof, 2009; Doig et al., 2009).

Understanding the intricacies of these systems and the unique experiences of parents and caregivers is crucial. This knowledge can inform the development of targeted interventions and support mechanisms that address the specific challenges faced by parents and caregivers within the child welfare and special education systems. By addressing these challenges and providing adequate support, policymakers and practitioners can work towards creating a more accessible, inclusive, and supportive environment for parents and caregivers.

Conceptual/Theoretical Framework

This research explores the experiences of caregivers who are involved in the child welfare and/or special education systems. I used Yosso's (2005) Community Cultural Wealth Theory as my theoretical framework, which helped in understanding the various forms of cultural knowledge, skills, and resources caregivers possess and utilize in these systems. This theory guided the study design and provided a framework for analyzing the data collected during the research process. By employing this framework, I gained a comprehensive understanding of these caregivers' challenges and strengths when navigating these complex systems.

Conclusion

Caregiver involvement and/or engagement is a multifaceted and complex concept, influenced by various factors that create barriers for many caregivers. While existing research predominantly focuses on caregiver involvement in schools (Epstein, 2001), there is a need to expand our understanding by examining the involvement of caregivers who are simultaneously engaged in multiple systems. This dissertation contributes to this broader understanding by investigating the caregiver involvement of individuals involved in the child welfare and special education systems. By exploring the experiences, barriers, and supports to caregiver involvement from the perspective of these caregivers, this research sheds light on their unique challenges and facilitates the development of effective strategies to enhance caregiver involvement in both the CWS and SES. Ultimately, such insights can inform the creation of more inclusive and supportive environments that empower caregivers and promote positive outcomes for children.

CHAPTER THREE: METHODS

Research has shown that students with disabilities in the CWS often face negative consequences in terms of their mental health and academic performance (Lee et al., 2018; Sanders & Fallon, 2018). While these students navigate the intersection of the CWS and the SES, their caregiver's involvement and engagement prove vital for providing them support, particularly when achieving the objectives outlined in their IEPs. The study undergirding this dissertation investigated the experiences of diverse caregivers of children with disabilities within the child welfare and/or special education systems.

Research Questions

The following research questions guided my study:

1) What are the experiences of caregivers navigating the child welfare system and/or the special education system?
2) What sources of support do caregivers utilize when navigating the child welfare system and/or the special education system?
3) What barriers do caregivers navigating the child welfare system and/or the special education system encounter and what advocacy strategies do they use to overcome those barriers, if any?

Research Design & Rationale

In this qualitative study, semi-structured interviews were employed as the chosen research method. The primary aim of the study was to gain a deeper understanding of the experiences of caregivers involved with the child welfare and/or special education systems. Interviews were selected as the most suitable approach for this study as they provided the opportunity to delve deeply into the caregivers' experiences, perspectives, and emotions regarding their engagement with CWS and SES. Furthermore, the study explored the strategies and resources caregivers identified as beneficial for effectively navigating obstacles within these two systems.

Population & Sample

Initially, my recruitment efforts for caregiver participants were focused on a small, rural school district located in Kern County, California. However, this site proved to be challenging as it produced only one participant. Recognizing the need to expand my site selection, I sought out alternative avenues to reach a more diverse population of caregivers. In my search for additional participants, I reached out to the California Association of School Social Workers (CASSW), a state-wide organization dedicated to supporting social workers in educational settings. This approach helped me reach a wider network of potential participants thus I was able to find another 14 participants for my study. In total, the sample size for this study was 15 caregivers. Six (6) were engaged in the SES, four (4) had previous involvement with the CWS, and five (5) had been involved in both systems.

A significant number of the CASSW participants were likely college-educated in that some mentioned having bachelor's degrees, while others had master's degrees. As a result, the participants generally had higher education levels than the average population. They also demonstrated a strong interest in advocacy as CASSW supports various legislative agendas. Additionally, many of these participants worked in professions such as school social workers, mental health therapists, case managers, and social service workers. These backgrounds suggest that they may have more knowledge and experience in navigating the child welfare and special education systems as compared to other caregivers. Furthermore, the fact that many of these participants had careers in higher-skilled professions also implies that they may not be facing poverty as are other caregivers.

In order to gain recruitment access at the small rural school district in Kern County, I first connected with the district's Superintendent. She provided approval, then connected me with the Director of Special Education who then distributed my recruitment flyer to eligible parents. Initially, there was no response, however, after utilizing the parent portal, I found one participant from the District. This collaborative approach allowed me to navigate the challenges of participant access, ultimately securing a participant from one of their school sites.

Access and recruitment from the CASSW involved establishing a connection with its President who enthusiastically granted approval for me to recruit participants through its network of school social workers. The President played a key role in my success by emailing my personalized recruitment letter to all CASSW members. This approach proved highly successful as I was able to procure the remaining fourteen (14) participants needed for my study. Participants included CASSW members and caregivers who received my recruitment flyer.

Data Collection

The data collection process for research questions RQ1, RQ2, and RQ3 involved conducting semi-structured interviews with caregivers. These interviews focused on capturing the emotions, perceptions, and experiences of caregivers as they engaged with both the CWS and the school system. Additionally, the interviews explored the barriers encountered and strategies employed by these caregivers to effectively navigate and engage with both systems, while also identifying any further support they may have required.

To facilitate open-ended dialogue and accommodate any emerging information, the interviews were conducted in a semi-structured format. The duration of each interview ranged from 30 minutes to an hour, depending on the extent of information shared. The interviews were conducted virtually via Zoom. The sessions were recorded using the internal recording feature of Zoom, with an additional backup recording on an iPhone. As necessary, I took notes during the interviews using a notepad.

Data Analyses

The data recorded from the Zoom interviews was transcribed using Otter A.I. Subsequently, I reviewed the transcriptions to ensure accuracy and made necessary corrections. The Zoom interviews were transcribed and the transcripts were coded. The coding process involved three cycles: first, descriptive coding techniques were used; in the second cycle, pattern coding was employed; and, in the third cycle, the codes were further categorized into themes following Saldana’s (2013) methodology. The coding cycles focused on capturing the shared experiences of the caregivers identifying potential barriers mentioned by these caregivers, and noting the supports that these parents found useful. To guide the data analysis, Yosso’s (2005) Community Cultural Wealth Framework was applied.

Positionality & Ethical Considerations

My study presented ethical issues, including concerns regarding my role as the researcher and potential participant confusion. There was a possibility that participants might mistake me for school staff, potentially influencing their level of participation and the feedback received. To address this issue during interviews, I introduced myself as a UCLA doctoral student and positioned myself explicitly as a researcher.

As part of the study, I collaborated with the school district’s staff and members of CASSW to promote participation, ensuring their understanding that involvement was voluntary and that they should not coerce or mislead caregivers into participating. It was important to clarify that specific participant responses would not be shared with them.

Another ethical consideration arose from the selection criteria for participants, with caregivers who had prior involvement in the CWS being considered potentially vulnerable due to their previous experiences Asking them about their encounters within the CWS had the potential to elicit negative emotions. To mitigate this ethical issue, participants were provided with a consent form that outlined the potential risks of the study, explicitly mentioning my status as a mandated reporter. This allowed participants to make an informed decision about their involvement. Emphasis was placed on the voluntary nature of participation, with the assurance that they could withdraw at any time.

In cases where participants became overly emotional or triggered during the interview, options such as pausing or taking a break were suggested until they felt ready to continue. Participants were also assured that all recordings and transcripts would be deleted upon completion of my dissertation, with no identifying information shared with third parties.

Credibility & Trustworthiness

The two main credibility threats to the study were bias and reactivity. Reactivity was a concern in two ways. First, there was the possibility that the selected caregivers for the interviews might provide answers they believed I wanted to hear due to my position as the researcher. These caregivers had prior involvement in systems where telling the truth could lead to negative consequences. The interview protocol included questions about their experiences and barriers encountered while navigating the CWS and the school system. Secondly, there was a concern that the answers obtained might focus on specific aspects of their experiences, potentially limiting the overall understanding. To address these reactivity concerns, it was emphasized that each caregiver had unique experiences in navigating the two systems, and my role as the researcher was solely to listen to their stories from a nonjudgmental perspective.

The second credibility threat anticipated was bias, particularly my own. As a former school social worker, I had worked with students who were involved in both the CWS and had disabilities. In this role, I was a mandated reporter, thus I often had to report parents to Child Protective Services because of child abuse and neglect. To mitigate this credibility threat, it was important to keep my own bias out of the questions and avoid leading the participants to answer in a way that supported my assumptions. Since the objective was to understand the experiences of the caregivers, the interview protocol needed to maintain neutrality while effectively addressing the research questions. Seeking feedback and recommendations from my co-chairs was undertaken to ensure neutrality in framing the questions. Additionally, piloting the interview protocol was conducted to gain a better understanding of how the questions might be interpreted and received by the participants.

Study Limitations

It is important to note that the results of this study were not representative of all caregivers across the state of California. Instead, the study aimed to collect rich data to better understand these participants and their unique experiences, particularly with the CWS and the SES. This research offers a unique contribution to the existing literature on caregiver engagement by examining the experiences of caregivers who navigate two distinct systems. While previous research primarily focused on caregiver engagement within the school system, my study shed light on the challenges and insights of caregivers who navigate both the school system and the CWS, providing valuable insights into their experiences. However, it is important to recognize that further research in this specific area is needed to make more general claims.

CHAPTER FOUR: FINDINGS

The purpose of the study undergirding this dissertation was to better understand the experiences of caregivers engaging and navigating the CWS and/or the SES. In this chapter, I present the study's findings as guided by its three research questions:

1) What are the experiences of caregivers navigating the child welfare system and/or the special education system?

2) What sources of support do caregivers utilize when navigating the child welfare system and/or the special education system?

3) What barriers do caregivers navigating the child welfare system and/or the special education system encounter, and what advocacy strategies do they use to overcome those barriers, if any?

To answer these questions, I conducted interviews with 15 caregivers who had a child with a disability currently enrolled in a special education program (6), had previous involvement with the child welfare system (4), or both (5). The reasons for participants' involvement in CWS varied across participants and included those who a) were currently receiving cash aid support and supplemental nutrition assistance, b) had been previously involved in a foster-to-adopt program, c) were providing kinship care, or d) had a previous open CPS case for allegations of abuse and neglect. The children of these caregivers had a range of disabilities that qualified them for special education services, such as autism, developmental delays, scoliosis, emotional disturbance, intellectual disability, ADHD, and speech delays.

While this study did not explicitly focus on the racial or ethnic backgrounds of the caregivers, it is noteworthy that all but one participant identified as Latino/a/x, with the remaining participant identifying as white. It is important to acknowledge that when discussing parent engagement and involvement in this study, the terms “caregiver” and “family” are used interchangeably and encompass non-biological caregivers, i.e., those involved in kinship care arrangements and participating in foster-to-adopt programs.

I initially aimed to explore the experiences of three specific groups: caregivers navigating the CWS, caregivers navigating the SES, and caregivers navigating both systems. As the study concluded, it became evident that while these participants had distinct experiences, the themes in the findings were mostly similar, with some subtle variations and noteworthy differences. Due to the shared themes across the groups, I chose to combine all three categories of caregivers involved in child welfare, special education, and both systems into a single category of findings, discussing all three groups as a whole while acknowledging distinctions when necessary.

Using Yosso’s (2005) Community Cultural Wealth Framework, the study identified four key themes from the interviews: 1) caregiver aspirations for their children, 2) caregiver emotional experiences, 3) caregiver challenges with the system, and 4) caregiver engagement as a tool for advocacy which included the resources they utilized. These themes provided a comprehensive framework for analyzing the narratives shared by the participating caregivers and gaining insight into their experiences within the CWS and/or SES. The results revealed striking similarities in the experiences of caregivers, irrespective of which systems they had navigated. In this chapter, examples from participants are utilized to emphasize the commonalities observed in their experiences.

Caregiver Aspirations for their Children

During the interviews, participating caregivers were initially asked to highlight their children’s strengths and articulate their aspirations for their future. These discussions revealed the distinct strengths displayed by each child, underscoring their individuality and diverse capabilities. Although there were slight variations in the specific aspirations expressed, a consistent overarching theme emerged: all 15 caregivers shared a common desire for their children to lead happy and successful lives. The caregivers expressed their hopes for their children, underscoring the significance of their well-being and overall fulfillment. This theme directly relates to Yosso's (2005) concept of "aspirational capital." This collective caregiver outlook reflected a universal aspiration for their children to thrive and achieve personal fulfillment across different aspects of life. One of the prevailing sentiments that emerged across all responses, as summed up by a caregiver navigating the SES, was, "I think we just want them to be happy and healthy; we want them to be well educated; we want them to be kind and loving to others." Despite minor differences, this common goal reflected a unanimous longing for the happiness, achievements, and overall fulfillment of the children. Regardless of the situation, be it their child having a disability, being involved in the CWS, or both, there was an overwhelming desire for education and personal success. A CWS caregiver passionately explained her insistence on education:

> I do talk a lot about education with them. So that's just something that, I guess, it's just, it's a must. It's already like, "This is where we are going," like, "There's no other choice." Even though I kind of say, "Well, if you don't want to," but no, that's basically, like, what I want them to do. I want them to go be successful leaders.

On the other hand, another parent, one of a child with a disability, conveyed the desire that her child live her best life:

> Oh my gosh. I want her to pursue her dreams. I want her to go to college. I want her to have the best life that she can. I want her to, uh, to be happy and do what she really wants to do in life.

However, recognizing the practical limitations, another caregiver with a child involved in both the CWS and having a disability conceded:

> We did want him to go to college. But we realized with his disability… it might not be possible, like, right away. And so that was our family’s, kind of like, push. But as time went on, as he went on with high school, it was kind of clear that that, especially university level, it wouldn’t be; he wouldn’t be ready at the moment.

Despite these varied situations, the essence of the caregivers’ wishes remained consistent – to see their children become self-sufficient. A caregiver engaged in both systems best summed up this sentiment:

> … to be independent, whatever that means for them. To be independent, to be on their own. To be able to, where I don’t have to worry if they have anything to eat if they have a roof above them. That’s, that'll be it for me.

These different perspectives reflect the shared aspirations and dreams that all sampled caregivers had for their children. They all desired happiness, success, and personal fulfillment for their children, regardless of the challenges they faced.

Caregivers’ Emotional Experiences with Navigating Systems

As interviews progressed, caregivers shifted their focus from their children to recounting their personal experiences while navigating the CWS and/or the SES. Although each caregiver's story was unique and each faced her own individual challenges, a common theme emerged: the intense and predominantly negative emotional experiences encountered while engaging with these systems.

Among the emotional experiences shared by most participating caregivers, several recurring themes emerged: denial, anger, depression, isolation, stress, and – ultimately – acceptance. These emotions were prevalent and significant components of the caregivers' journeys, shaping their perceptions and reactions as they grappled with the complexities and challenges inherent in navigating their respective systems.

Caregiver Denial & Anger

A majority of caregivers across this study reported experiencing senses of denial and/or anger at various stages of engaging with CWS and/or SES. Most caregivers experienced these emotions most strongly when they first learned about their child's disability through the SES or when they discovered that they were under investigation for child abuse by the CWS.

It is important to note that while denial was commonly experienced among all caregivers, there were significant variations in how denial was understood and manifested by caregivers depending on which system(s) they were navigating. For instance, caregivers involved in the CWS often encountered denial as a reluctance to accept their own responsibility for the circumstances leading to their investigation by CPS. On the other hand, caregivers navigating the SES frequently faced denial in the form of resistance to acknowledging their child's disability, often experiencing disbelief, and sometimes directing blame toward themselves or the system's providers. Therefore, although denial emerged as a prevalent theme among the majority of caregivers, the experience of denial was not uniform across the different caregiver groups.

One caregiver vividly expressed her distress upon receiving her child's autism diagnosis:

> I think I was in, like, *denial* of like, well… I think emotionally, I was going through a lot, and not wanting to accept that [my child] could potentially have autism. And so, although it's been an emotional time, because I continuously get asked the same questions about his deficits, which is hard to, like, say – it's like, you know it, but then when you're saying it out loud to someone you don't know; it is really hard. And then they're just like, telling you that your child has X,Y, and Z. That's difficult to hear (emphasis added).

This caregiver's distress was not only caused by learning about her child's condition, but also the repeated recounting of her painful story and the focus on her child's deficits by various service providers. Expressing her frustration, she further stated:

> People continuously ask you the same questions that you are kind of in *denial* about and make you sad and make you feel like, man it's my child, then… sorry to say it this way… [who's] not normal. And it felt horrific to continuously have to do with the same assessment over and over again (emphasis added).

Another caregiver also involved in her child's special education program echoed these sentiments:

> And then, when he was in preschool, it started all over again. I was a little bit more in *denial*, you know? I was like, "No, I see him, he's doing better." It was hard for me, you know, just to understand that (emphasis added).

When this caregiver first learned about her child's diagnosis, she not only experienced a sense of denial but went on to share that she had been so angered by her experience with the staff that she took action to remove her child from the school that had provided the diagnosis. This caregiver described her experience with the school's speech therapist:

> She told me straight out, you know, she didn't say [she had] concerns. And that day, I remember, I even stopped, you know, he stopped doing speech therapists because, you know, I don't know, it just, like, hurt me, you know? So, I still, like, I actually got somebody else for him.

This caregiver was okay with her child receiving speech services, but shared that doing so was emotionally overwhelming when told of the official diagnosis. She remembered:

> … just crying so much, you know, because I'm like, maybe, I don't know, that it's something else. So okay, you have to accept it, you know? This is your child. […] It was like an eye-opener for me.

One caregiver, having had an negative encounter with the CWS, recalled her feelings of denial and anger towards the assigned county social worker: "I don't think I should have a case open. You should just close it already. Like, I don't see why you guys are investigating me like you should be on him and not me." This caregiver described how she was initially in denial about her situation and was angry that the social worker focused on her and not her husband. She shared why the social workers became involved and opened an investigation:

> Their dad was a substance abuse user, meth. And so, during the whole addiction and binge episode, and so on, there was a lot of aggression on his part. And during me trying to help him out of it, you know, cops got involved when he, you know, got aggressive and so on. And if the kids were there, that's when they had to call [CPS] and open up a case. And so we were, yeah, so we had an open case, I think. So, the allegations against me were endangering a child. Because I would let him come and be involved when I suspected he was sober. But you know, in the child welfare system, that's like, no, if he

> has used and he’s not allowed to be around the children. And so that’s why they opened up the case.

Later on, she recognized her own role in the situation, acknowledging her personal journey from denial and anger to eventual acceptance and understanding. This pattern of emotional progression was also observed among numerous other caregivers in the study.

Caregiver Depression & Isolation

During the interviews, participating caregivers highlighted the challenges and numerous barriers they faced when navigating the CWS and/or the SES. In addition to these difficulties, caregivers also shed light on the impact of this experience on their mental health. A common theme emerged, with many caregivers expressing feelings of depression, isolation, and stress as they engaged with and struggled to navigate the intricate aspects of these systems.

One participating caregiver, engaged in her child’s special education program, summed up the prevailing sentiment that emerged across many responses:

> I feel like I went through a little bit of a *depression*, going through it, and it was like, super emotional. […] I think that was hard, definitely difficult. And then also going through the process was so difficult. And I feel like I felt *overwhelmed*, *depressed* sometimes. And I just wanted someone to talk to (emphasis added).

Like this caregiver, several others spoke of feeling depressed, being overwhelmed, and experiencing loneliness as they interacted with and navigated their respective systems.
One caregiver, who was part of the CWS, reflected on her encounters with the investigating county social worker: “I was diagnosed with *depression* and *anxiety*. And so, they just said, ‘Okay, well, if your mental health is an issue, you need to keep up with your mental health treatment’ (emphasis added). The caregiver further explained that her

social worker did not validate or recognize her feelings of depression, and, eventually, she just stopped sharing how she felt. When asked how she was feeling, she said all she would say was, “I’m fine.”

In a poignant account, a participating caregiver involved in the CWS and providing support for a child with severe emotional disabilities expressed that her experience with the CWS was not only isolating and overwhelming, but also inflicted severe distress on her entire family:

> That was hard, emotionally that I was in (that) role, of course. So, because we loved him so much – he was our son from day one – but it was really destroying our family. It was getting to the point where my husband and I were almost going to be divorced.

She extended her narrative to explain how county social workers perpetuate problems like hers. Her struggle to access resources for her disabled son and support for her family exemplified the sense of isolation felt by many caregivers. She detailed her overwhelming and lonely experience:

> I didn’t take care of myself. I tried as much as I could, but it was very difficult. I put him first. And that’s one of the reasons why we had to also relinquish because it was getting to the point where I was neglecting myself in all [areas of my life]. I cried a lot *by myself*. And with family, you know, I had some good friends that, you know, that were very supportive with me as well. But it was very *lonely*, I can tell you that. Very *lonely* (emphasis added).

It is worth noting that one caregiver experienced a decline in her mental health, which worsened her depression, due to her negative experiences with CWS. Her case serves as an example of how the intricate nature of these two systems can amplify pre-existing mental health conditions, further burdening the caregiver emotionally. These caregivers' stories emphasize the emotional and mental health toll experienced by most caregivers as they navigated these systems.

Caregiver Acceptance

In their journey through the CWS and/or the SES, several caregivers arrived at a point where they accepted the processes, protocols, and expectations imposed by each respective system. Additionally, numerous caregivers who initially denied their child's disability also experienced a shift in their perspective, expressing acceptance towards their child's limitations. Once again, it is important to note that while acceptance was commonly experienced among all caregivers, there were significant differences in how that acceptance was experienced depending on which system(s) they were navigating. For instance, CWS caregivers often encountered acceptance by acknowledging their own responsibility for the circumstances leading to their investigation by CPS. On the other hand, caregivers navigating the SES regularly discussed acceptance in the form of acknowledging their child's disability and accepting his/her limitations. Therefore, although acceptance emerged as a prevalent theme among the majority of caregivers, the experience of acceptance varied.

One caregiver of a child with a disability, who had been intensely focused on addressing her children's academic deficiencies, shared:

> It got to the point where this year I said, "At least one day out of the week, you guys have to do some sports. Like we're… we have to do some extra activities because you guys are not getting anything." And we [are] still not learning, we [are] still not getting what we need to get.

This caregiver had spent countless hours every day drilling her kids on academic subjects, only to realize the approach was not helping. She reached a point of acceptance – she accepted that her children continued to struggle academically but that they shouldn't miss out on other facets of childhood for the sake of perfect academic scores. She came to terms with the reality of their disabilities and realized she needed to adjust her expectations.

One caregiver engaged in both systems expressed his realization by saying, "I've learned through going through all of this, that you have to trust the process. And there will be change, and there will be improvement." Initially hesitant about the process, this caregiver learned that although complicated and stressful at the beginning, the IEP his son was given through the special education program turned out to be a great support for his son's academic and social development. Similarly, another caregiver who had a child with a disability expressed her observations:

> I have seen a lot of improvement in my son since he started [his IEP]. I think that at the age of four he began his speech therapy… has helped him a lot. So, I think this program helped us a lot.

Another caregiver, who initially faced challenges in coping with her son's special education needs, shared her experience: "I feel and I see tremendous progress – I cry from sadness, but I cry out of happiness, also, because I see the support." She further expressed that her son's IEP team, combined with her own support system, played a crucial role in facilitating her child's progress. One caregiver who navigated the CWS expressed a sentiment that resonated with many other participating caregivers: "… but in terms of the process, it seemed arduous and illogical at times. But I always came around to understand that there was a method to whatever they were doing."

Several caregivers acknowledged and grasped the significance of accepting their children's limitations as an internal process that was difficult yet essential for progress. A caregiver actively engaged in both the SES and CWS provided an honest assessment of himself:

> I think the main challenge is me – me changing my mindset. I grew up very academically focused and very passionate about school and doing well. And neither of my kids shares that at all. There's a lot of apathy towards school. And so that's what we've been focused on the most, trying to change that, trying to get them excited about school and learning. And we've had a mixed bag this year because our youngest is obsessed with video games right now. And so, we casually said, "If you get straight As that you'll get… you can get PS5." Fully, like, knowing that there's no, there's no possibility of that.

This caregiver reflected on his earlier aspirations for his children, mainly his desire for them to excel academically. However, he also recognized and accepted the challenges faced by his children, which prompted him to reconsider his expectations. He acknowledged his need for personal growth and pledged to shift his own mindset to provide better support for his children.

Another caregiver, who was actively involved in both the CWS and his child's special education program, shared his perspective about accepting his role within the system:

> Your role is not to come in on your white horse and save the day. Your role is to be a positive influence in these kids' story for however long that may be and stay really focused on empathy with the birth family and understanding that you don't know what they've been through, you don't know what they're going through.

Though by different avenues, these caregivers experiences illustrate a collective journey toward acceptance of their roles in the child welfare and/or special education systems.

Caregiver Stress

Many caregivers in this study expressed not only feelings of depression and isolation but also the significant stress associated with managing the day-to-day support of their children with disabilities and/or navigating the demands of the CWS and SES. One caregiver of a child with a disability detailed the substantial stress induced by the conflict between her work hours and her child's speech therapy sessions:

> I have a full-time job. I luckily work from home. But like, all of these [speech] sessions were, like, during my work time hours. It was super, like *stressful*, like *super stressful*. I had to, like, leave work… It takes a *huge toll* on you. Physically, emotionally, it's a lot of work (emphasis added).

While this caregiver was lucky to occasionally receive assistance from her mother, she found her son's special education program did not cater adequately to the requirements of working caregivers. She wondered about how feasible it was for parents with less support to meet the system's extensive demands. Another caregiver, heavily involved in her children's special education program, echoed a similar struggle in supporting her child's academic needs at home:

> That's also *taking a part of me*, like doing the research, how to teach you to break this number and then do it into this way of math that they're doing. So, I think that that is *hard on the parents* when they're expected [to do] that – I know that as parents, we have to help our kids. We're also expected to work with them. It takes *a lot on the parents*, especially working parents, that you get home and you

> don’t want your kids to be eating junk food all the time. So, we’re trying to give them more and provide a healthy meal. But that takes time too. Cooking and then cleaning (emphasis added).

In addition to addressing the stress related to supporting her children’s academic needs and completing daily household tasks, this caregiver also expressed that she frequently lacked time for self-care. She further explained that this lack of self-care resulted in additional stress.

One caregiver described the stress she experienced trying to understand the legal aspects and associated difficulties of the CWS:

> There was some stuff that I knew. And just other stuff that I didn’t know. And I just wanted to make sure that I was writing everything, and it was *overwhelming*. And I’ll be truthful. Like, if I did not have my training on restraining orders and knowing, like, the legal aspects of certain things, I probably would not know how to do any of it (emphasis added).

This caregiver’s reflection highlights the significant challenges many face when navigating the CWS, particularly in comprehending its legal aspects; not having full knowledge of the system leads to a feeling of stress.

My research sheds light on the shared experiences of caregivers, regardless of their involvement in the CWS, the SES, or both. Examples from participants in each group highlight the commonalities observed in their journeys. Caregivers expressed their aspirations for their children, emphasizing the universal desire for their children’s happiness, success, and personal fulfillment. However, navigating these systems came with significant emotional experiences, including denial, anger, depression, isolation, stress, and eventual acceptance. Caregivers faced numerous challenges and barriers, leading to feelings of depression, isolation, and stress. The study underscored the importance of understanding the collective experiences of caregivers and the need for effective support systems to enhance their well-being as they advocate for their children.

Barriers to Navigating the Child Welfare & Special Education Systems

As interviews progressed, focus shifted from exploring caregiver experiences to examining the challenges they encountered when engaging with and navigating the CWS and/or SES. Throughout our discussions, participating caregivers identified a multitude of barriers that hindered their interactions with these systems which included bureaucratic complexities, informational gaps, and difficulties in understanding the procedures and protocols involved. What made this paper's findings particularly noteworthy was that, despite the high level of education among many of the study participants – with many holding bachelor's degrees or even graduate degrees – they all expressed the unanimous sentiment that these systems were convoluted and arduous. The caregivers' educational backgrounds served as a testament to their intellectual capabilities, and yet, even armed with their academic achievements, they encountered significant challenges in comprehending and maneuvering through the systems' intricacies.

The experiences of caregivers in this study, whether navigating the CWS or the SES, were remarkably similar in terms of the challenges they faced. Despite the different contexts and objectives of these systems, caregivers encountered comparable barriers, such as a lack of information, unfamiliarity with processes, difficulties in understanding and participating in decision-making, inadequate support from service providers, and communication gaps. These shared experiences indicate that caregivers confront common obstacles when engaging with either system, highlighting the need for comprehensive support and improved navigation resources across both systems.

Caregiver Challenges across Systems

The interviews revealed a clear message: irrespective of their educational backgrounds, caregivers encountered numerous barriers while engaging with and navigating the CWS and/or SES. These barriers stemmed from the inherent complexities of the systems themselves, as well as through challenging interactions with certain service providers. Additionally, the adverse effects of the COVID-19 pandemic further compounded these difficulties, making caregivers' involvement in these systems even more challenging and burdensome.

Although many participating caregivers navigating both CWS and SES shared that they ultimately reaped some benefits from their engagement with their respective systems, most caregivers in both systems initially discussed how complex and difficult the systems were to navigate from the onset of their engagement in them. Many participating caregivers noted that they were not provided with enough information or resources to successfully navigate and engage. And, even though about half of the participating caregivers in this study had jobs in education and/or social services (e.g., social worker, case manager, teacher), they reported not being aware of the complexities each system entailed.

A CWS caregiver exemplified the difficulties experienced by most caregivers in this study. Initially, she requested support from her social worker but did not receive the required information or referrals: "Well, I don't know who to turn to for help. I thought that. Well, I asked the social worker, 'I've heard that sometimes they help look for therapy or resources.' But she was not helpful with anything." This caregiver shared that she finally realized how to connect herself and her family to therapy long after her CWS involvement was over. She discussed how her experience helped her become more engaged in her children’s school and eventually learn about the various community resources from other staff members. The experience of this caregiver exemplifies Yosso’s (2005) concept of navigational capital, highlighting how many caregivers in this study were compelled to independently navigate their respective systems due to the barriers they faced.

Challenges with Service Providers

Throughout my study, the experiences of participating caregivers revealed striking similarities in encountering significant barriers while engaging with and navigating the SES, the CWS, or both. These barriers predominantly stemmed from negative experiences involving system providers and representatives. Caregivers expressed a range of challenges, including inadequate services, a lack of prioritization, being disregarded as experts, not being treated as partners, and, in certain instances, a lack of responsiveness to their unique family needs. Throughout the study, caregivers consistently echoed a theme of dissatisfaction with specific service providers. These caregivers expressed profound disappointment, describing their interactions with these providers as unhelpful and the services received as inadequate. These encounters had a profound impact, exacerbating the already challenging and frustrating nature of their engagement with their respective systems.

Inadequate Services & Support

Caregivers often recounted instances wherein their concerns were dismissed, their questions unanswered, and their pleas for assistance were met with indifference. They expressed a sense of frustration and helplessness, as their efforts to navigate the system(s) were rife with roadblocks created by the very service providers who were supposed to be their allies. These shared experiences shed light on the profound impact of service providers’ shortcomings. Rather than feeling empowered and supported, caregivers were left to navigate a complex and overwhelming landscape with limited guidance and assistance, their frustrations amplified as they faced additional obstacles and were forced to expend more time and energy advocating for their children's special needs.

A caregiver who had experienced an involuntary child welfare investigation shared her frustration about the limitations of the service provider assigned to her:

> Honestly, I felt like, at least for me, I didn't benefit because, again, the services were *limited*. The quality that I got from the family preservation worker [provider] was *pointless*. […] I feel like she *didn't really provide anything*. Because I think she thought, "Oh, well, you're easy." Like, "You listen to the rules." And she would basically just call me to check in on the kids for, like, a couple of minutes, and then hang up. I feel like maybe *we could have gotten more out of it.* And *maybe I wouldn't be so defensive* over it (emphasis added).

She further expressed that interactions with the provider lacked an authentic connection and felt more like a procedural process wherein her needs were not truly addressed. She also shared that she did not feel prioritized by the provider, possibly due to being a compliant and non-disruptive client.

Multiple caregivers of children with disabilities expressed their concerns about service providers failing to deliver the appropriate services as specified in their child's IEP. This lack of support posed significant challenges for their children and added complexity to the caregivers' involvement with the SES. Several participating caregivers of children with disabilities shared their experiences of not being provided the appropriate services outlined in their child's IEP.

This not only created various challenges for their children but also complicated the caregivers' engagement with the school system.

In some instances, caregivers expressed a belief that the service provider assigned to their children disliked working with them, often ending sessions prematurely. A caregiver having issues with her child's IEP provider shared:

> She would only spend, like, ten minutes with [my child]. And this particular therapist… she was not providing the proper services. Nor no one was, like, supervising her. No one was, like, asking me questions on how she was doing, nothing, like, and it's my fault.

This example demonstrates the detrimental impact of inadequate service providers on caregivers' experiences, the consequences of such shortcomings evident in the lack of progress made by the children and subsequent challenges faced by caregivers when engaging with the system. Another caregiver with a child with a disability echoed this sentiment, feeling that her son's therapist displayed a clear lack of enthusiasm for his work and made no effort to establish a connection with her son during his sessions. She expressed that her son was eventually assigned to a different therapist who managed to genuinely connect with him, but that initial experience complicated the process for both her and her son. These caregiver experiences shed light on the frustrations and limitations faced by many caregivers in receiving inadequate services from a service provider within their respective system.

Many nonbiological caregivers involved in both the CWS and the SES faced significant challenges in obtaining educational rights for their children. These challenges stemmed from the inadequate information provided by service providers and their unwillingness/inability to collaborate with the opposing system. Obtaining educational rights became a major barrier in navigating the SES and securing necessary support for the children. Complicating matters further, educational rights were granted through the CWS, leading to limitations on the support and information available from the education system. Despite having legal custody, some caregivers lacked the authority to make education-related decisions due to the absence of educational rights, including the ability to request or sign an IEP. They struggled to understand the process of obtaining educational rights as they faced difficulties in finding information and encountered a lack of communication between the two systems.

As one caregiver navigating both systems expressed:

> We felt like we were this liaison between these two walled systems… in your work, you have a problem between two entities, like the solution is you just bring everybody together and you resolve it. And those are the types of things that just aren't, don't seem possible or feasible in this world. I don't think it's from the District, I think it's from the [CWS] side.

In this specific case, the caregiver highlighted a significant issue with the lack of communication and collaboration between the Department of Children and Family Services (CWS) and the District's SES. Despite the caregiver's efforts to have both systems work together so to address his child's special needs, the necessary information sharing and coordination did not occur. The caregiver believed that a straightforward solution was to bring both systems together and develop an action plan for her child until she obtained educational rights. However, this collaborative approach was not implemented, leading to further complications in the caregiver's engagement with both systems.

Lack of Necessary Information

Many caregivers consistently expressed their lack of awareness regarding the logistical details and procedures necessary to navigate their respective systems. They attributed this lack of knowledge primarily to their service providers' failure in providing them with the necessary information.

One caregiver shared her experience of requesting an IEP for her son. She was instructed to submit a letter requesting an assessment but received no guidance on the required format or submission process. She recalled, "I didn't know that I needed to [date] stamp the letter the first day because it [was] for an IEP. I was just gonna' turn it in." Luckily a friend who had gone through the process advised her: "No, make sure that he stamps it because they have 50 days to respond to your letter." According to this caregiver, a significant number of parents do not receive timely support because they simply do not know to date or stamp their request letter. She believed schools take advantage of this technicality so to prolong the response time, causing further delays in obtaining the necessary assistance.

In some instances, caregivers shared that a lack of information resulted in their child not receiving services when needed. One caregiver navigating the challenges of the special education system reflected on her experience:

> I didn't get connected to the regional center because, by the time that I realized that she was already past three years old, and the regional center only services kids up until three years old. That was frustrating [for] me because I would have been able to provide services for my daughter even at a much younger age. So that's something that I still beat myself over – that even as soon as I realized that when she was two I should have reached out to the regional center, and they're able to provide those services for free if need be.

This account highlights the shared experience of many caregivers who express regret and self-blame for not being aware of available services and not accessing them earlier for their child. It underscores the fact that this lack of awareness was largely due to the absence of guidance and support from service providers.

The experiences shared by several caregivers shed light on the lack of information and guidance they received from service providers. One parent who struggled to understand the intricacies of the SES highlighted this issue, stating, "I know my voice counts, and that as a parent, I know it's very powerful. But I don't know about the actual logistics." This caregiver expressed her lack of understanding about the services being offered and whether she had the ability to influence the number of IEP service minutes her child could receive. She was uncertain if the services provided were standard or if she could request additional support. Furthermore, she emphasized that no one within her child's special education program took the time to explain these crucial details to her.

A caregiver with a child with a disability, who also worked as a therapist in a school, admitted even she wasn't fully aware of the intricacies of the IEP process: "I don't know the logistics of it… I have basic knowledge of the IEP. But again, I don't offer IEP [services], so I don't know what the logistics are." She further shared that she experienced a disconnect during her daughter's IEP meeting, where she was considered a partner in the decision-making process but felt ill-equipped due to insufficient information regarding her daughter's services. She expressed a desire for a more structured guide with information, such as a handout outlining the different services available, to assist her in making more informed decisions.

Another caregiver shared the following experience of being involved in her child's IEP process:

> They always set goals, and I didn't know that we could change them. Because I guess just the way they would say it was like, ‘So this is the goal.’ And then they would say, ‘Oh, he could reach that, right? Like, you agree? You think that’s a good plan for him?’ And, you know, we always agreed.

She further shared that she always knew her child could not reach the outlined IEP goals, but agreed with the team anyway because she did not know how to disagree with them. She wished she had known more information about how to disagree with the services outlined in the IEP and how to incorporate information she knew about her son’s abilities into developing appropriate IEP goals for him.

Another caregiver of a child with a disability, who also worked as a social worker, recounted the first time she was given a referral for the regional center:

> I work in my professional setting as a social worker… I don’t know anything about the system, about the special education system. That is not something that I’ve actually… I’m not an expert in it. And in my professional field, I’ve never really dealt with that system. And so, when the nurse told me to call this number, I was just expecting to get more information of, like, what is the referral process.

This caregiver further described that this lack of information and preparation made the system’s process intimidating and challenging for her.

Insufficient guidance and support from service providers often left many caregivers feeling lost, overwhelmed, and ill-equipped to advocate for their children’s needs. The lack of awareness about available services, procedures, and rights further exacerbated their difficulties in obtaining appropriate support and services.

Not Prioritized and Ignored as Experts

Many participating caregivers in the study shared negative experiences with their service providers, highlighting a common thread in their interactions. Several caregivers expressed feelings of being overlooked and not prioritized by their service providers, attributing this treatment to their status as “model clients.” They described how their adherence to rules and guidelines, along with their compliance with the system’s requirements, seemed to work against them in terms of receiving the attention and support they needed. These caregivers believed that because they followed the established protocols and procedures, their providers may have assumed that they required less assistance or had fewer urgent needs as compared to other families. As a result, they felt their concerns were dismissed or downplayed, and their voices were not given the same level of attention and importance as those who were deemed more challenging or non-compliant. These shared experiences highlight a significant issue in the caregiver-provider dynamic wherein the perception of being a model client inadvertently leads to feeling marginalized and underserved.

One caregiver, who was simultaneously navigating the complexities of CWS and SES, revealed a significant insight: “I feel like they thought that because I was such a good advocate, that I was doing what I could and that they didn’t need to be there as much, I guess.” However, her dedication to advocating for herself and her children often seemed to create more difficulties than alleviate them:

> I had a background in social work [and] they were kind of *pushing me to do their job*. Which was pretty disturbing, because it was like, “Yes,” you know, “I do have a background in social work. But that’s not my job.” […] They were asking me to call, like, some of [my child’s] relatives, you know, some cousins, like any relatives, to see if they were willing to take him. I didn’t. I wouldn’t feel

> comfortable with it. And *even though I didn't feel comfortable, they continued to push* (emphasis added).

A common sentiment among caregivers was that they often felt disregarded as knowledgeable authorities in their children's lives, resulting in a perception of not being considered equal partners. One caregiver recounted her frustrating experience in advocating for additional service time for her child's IEP:

> I guess, what they did say? That it's though an hour is too long. So that wasn't an option. And as far as like the 30 minutes, I will say that I was a part of the decision-making, but it was kind of like, '*Well, this is what we're offering'* (emphasis added).

This caregiver felt that the decision-making process was neither balanced nor inclusive, and it seemed like the providers had predetermined goals that left her with limited choices. Another caregiver similarly expressed her dissatisfaction with the lack of partnership in her son's IEP process:

> I guess just that sometimes feeling like we're not a team, you know? I feel like they feel like they're the experts. *I'm not really fully listened to*. I felt like we're the experts on him. Like, I feel like I know everything about him. So not really taking what we say, like, into, like, more consideration, you know? I feel like *they see it as they're the experts* and they know (emphasis added).

She also expressed that she frequently felt disregarded by the IEP team, which often led to feelings of frustration. Another caregiver described her frustration with not being treated as an expert on her children during the process of requesting an IEP:

> If you’re telling them and you’re seeking out support, you know your child better. And when the school is telling you, “Oh, it could be this, it could be that,” I understand, sometimes, where their point of view is coming from. But I think for me, especially for my daughter, that it took a year for her to get an IEP, we lost all that year for her. And that was a struggle for me because *I knew since the beginning, and I was telling them*, and *they didn’t listen to me*. And it took a whole year for her to get support (emphasis added).

This caregiver expressed particular frustration with the administrator overseeing the IEP process, highlighting that her daughter lost a year’s worth of support and services due to the inefficient handling of her case.

These shared experiences highlight a pervasive issue in the caregiver-provider dynamic in which caregivers’ voices and expertise are not given the attention and importance they deserve. The perception of being a model client or an advocate can unintentionally marginalize caregivers and create additional hurdles in accessing the necessary support for their children. It is crucial to recognize that these experiences were not isolated incidents but rather were shared by many caregivers in the study.

Lack of Flexibility and/or Accommodations to Family Needs

Throughout the interviews, participating caregivers provided insightful examples that highlighted the inflexible nature of navigating the CWS and/or the SES. Many caregivers expressed frustration with the scheduling of meetings during work hours, which made it difficult for them to attend. They emphasized that service providers showed little flexibility or accommodation for working parents, creating additional challenges in accessing and participating in important discussions and decision-making processes. Furthermore, several caregivers shared that service providers had unrealistic expectations and did not consider the caregivers’ other obligations and responsibilities at home. The providers seemed to overlook that caregivers had to balance their children’s needs with household tasks, family commitments, and personal responsibilities. This lack of understanding and consideration made it harder for caregivers to fully engage and actively participate in the system.

In one specific case, a caregiver who identified as being in a same sex relationship shared his frustration about the IEP providers’ insensitivity to their family’s unique situation:

> The one negative thing about the IEP was because we are two dads. A lot of times, they would ask us, like, ‘Alright, what’s your… what’s his mother’s name?’ And we’re like, ‘There is no mother. He has two dads.’

This caregiver’s experience highlighted the failure of the IEP providers to recognize and respect diverse family structures, emphasizing the need for increased sensitivity and inclusivity in their interactions.

These caregivers’ experiences shed light on the pervasive and deeply ingrained challenges presented by the rigid and unaccommodating nature of the systems involved. The accounts shared by these caregivers highlight a systemic issue in which inflexibility and lack of accommodation hinders their ability to navigate and access necessary support and services for their children.

Lack of Communication with Service Providers

Throughout the study, a significant number of participating caregivers consistently voiced concerns regarding the lack of communication from service providers which posed significant barriers to understanding and navigating the CWS and/or SES. As mentioned earlier, some caregivers experienced this lack of communication from being perceived as model clients, thus not receiving the necessary prioritization. However, even in cases where regular support was needed from the school or CWS, a recurring pattern of poor communication between both system's service providers and caregivers was clear. These caregivers' shared experience highlights the pervasive nature of communication challenges faced by caregivers and the need for improved communication practices within these systems.

Several participating caregivers described trying to initiate communication with their service provider, only to be met with delayed and/or no response. One caregiver, who had experienced an open CWS investigation, expressed her frustration with a social worker: "When I tried to talk to him he almost never answered me." This lack of responsiveness and communication posed a significant challenge for her as it made it difficult to understand the expectations and requirements placed upon her. Similarly, another CWS caregiver, though in regular contact with her social worker, faced distress due to the poor quality of that communication: "She gave me a hard time, definitely. She was pretty bad. Like, she was not understanding at all. She was very aggressive." This caregiver said she felt always on the defensive and, at times, shut down because of how her social worker treated her.

Consistently, many caregivers highlighted this common barrier of lack of communication in their engagement with and navigation of the system(s). They expressed the need for regular communication to better support their child at home and to stay informed about their child's IEP progress or progress with their child welfare case. The absence of consistent and informative updates left them feeling disconnected and uncertain about how to best advocate for their child.

Many caregivers frequently encountered a disconnect in the way service providers communicated updates and information about their child or their case. In many instances, the providers opted for the easiest form of communication for themselves, which often proved to be unhelpful for the caregivers. One caregiver shared her experience of receiving a three-page report detailing her child's IEP goals and struggling to understand its contents. To her dismay, she did not receive any follow-up or clarification from anyone regarding the report. This left her uncertain about whether her child had achieved any of the goals set in the IEP. Similarly, another caregiver expressed their frustration with the lack of communication from a special education teacher: "I just get a report, but I haven't had that much of a communication with the special ed teacher." Another parent, who was in the early stages of getting her child assessed, expressed her sense of being lost due to the lack of communication from the assigned school psychologist. She shared her frustration, saying, "Nobody gives me, like, a response, because I don't need an exact answer, but, like, support, you know, as a parent. Like, how can I support my son right now, with the challenges that we're having?"

Many of the caregivers in my study consistently expressed challenges in accessing resources due to a lack of communication with their service providers. They often hesitated to reach out to their social worker or the child's service providers for assistance, preferring to seek resources independently or relying on support from close friends and family. This reluctance stemmed from the fact that service providers, particularly county-level social workers, did not prioritize building relationships with the caregivers. As a result, caregivers did not feel comfortable reaching out for help when they needed it. The absence of open lines of communication hindered their ability to access the necessary support and guidance, creating additional barriers in their caregiving journey. These challenges were commonly experienced by a significant number of caregivers, highlighting the widespread impact of inadequate communication between caregivers and service providers.

The recurring theme of inadequate support and communication from service providers had significant repercussions for caregivers, leading to delays, resentment, and additional challenges that could have been mitigated through clear and consistent communication. One caregiver reflected on her experience, acknowledging that she could have advocated more assertively for her child: “Looking back, I could have advocated for my child a little bit more. And I don’t know if it was, like, fear. I don’t know what it was that I didn’t want to reach out. But I should have.” This caregiver’s reflection highlights the missed opportunities and the realization of the importance of proactive communication in advocating for her child’s needs.

Exacerbated Challenges from the COVID-19 Pandemic

The onset of the COVID-19 pandemic presented an array of challenges to many caregivers who were already grappling with the child welfare and/or special education systems. These caregivers conveyed how the pandemic disrupted the services and support they were receiving, causing significant delays spanning several months. Furthermore, many of the crucial support agencies they relied on were forced to shut down temporarily, propelling a host of difficulties for these children and their families.

One CWS caregiver shared that her social worked recommended she attend a Narcotics Anonymous family support group; however, due to the pandemic, the support group was temporarily closed, leaving her without alternatives:

> I think maybe that would have helped me because I blame myself a lot for it. And I think I would have [attended]… it would have been easier if the pandemic didn’t happen. Because they kept telling me “Go to the meetings,” you know,

> "participate... you need to talk to someone. We could get you set. We can get you connected with somebody." It's like, "Okay, well, where are they?" You know, and I would only have the family preservation worker, and she was like, no help, either because of the pandemic.

This caregiver's experience exemplifies how the challenges faced during the pandemic, coupled with communication issues, significantly impacted the availability of crucial support and left her feeling unsupported in her journey. Another caregiver navigating both the child welfare and special education systems shared a similar experience, expressing that he had previously attended parent support classes before the onset of the pandemic, but the classes ceased entirely during – and after – the pandemic. He emphasized how he had relied on those classes for guidance and support, only to find himself suddenly without any resources.

In addition to the disruption of parent support classes, caregivers revealed that pandemic-related closures had significant implications for their children's access to essential special education services and assessments. Many discussed the delays they faced in obtaining the necessary support and evaluations for their children during this time. Furthermore, caregivers expressed how the pandemic had prolonged their involvement with CWS, exacerbating the challenges they already faced. These shared experiences demonstrate the widespread impact of the pandemic on the services and processes within both the special education and child welfare systems.

One CWS caregiver expressed frustration with the pandemic's impact on his family's court proceedings as it would determine whether he and his partner could proceed with adopting the children they were fostering. Reflecting on the delays caused by the pandemic, he stated, "I was getting a little annoyed at how long things were taking. Our court date because of COVID got pushed back a year. Like, we are not going to have court for twelve months." This extension was significant because, having already fostered their children for two years, they would have to continue monitored visits with the children's biological parents who often failed to attend the meetings and regularly shared false promises with the children. Another caregiver shared a similar experience in which her CWS investigation was extended by a year due to the court system shutdown; her case had been set to be closed, but now faced an additional year of being monitored by an unsupportive social worker.

Another caregiver, involved in the SES, shared her experience of her children's school using the pandemic as an excuse for not providing any support to her children. She noticed early on that things were not going well, and when she approached the school for help, she stated that their response was:

> "Oh, because of COVID." Like, we tend to blame everything on COVID, which is, is true. COVID did play a big part of it, but I noticed that my kids were struggling even before COVID, since they were 18 months.

During the pandemic, most study caregivers involved in the CWS and/or SES received virtual services. However, the majority expressed dissatisfaction with these virtual services, finding them to be inadequate and/or unhelpful for both themselves and their children. They reported that using platforms like Zoom for services and support introduced additional challenges because their children struggled to sit for extended periods and lacked the necessary technological skills. The virtual format became overwhelming and unrealistic for some participants as they were expected to provide academic support for their children while also juggling work responsibilities. A caregiver who had to work from home during the pandemic shared her challenging experience:

> COVID made it worse because now I had to be at home. We were all stuck at home. I had to work. And then the kids being on Zoom, the teacher was asking, “Turn the page into the book, turn to the page 375.” The kids knew, like, all the way up to 10. So how can you expect… and the teachers couldn’t support them. How do you turn the page? Um, so [I] had to support. [The children] needed the support and no one was there to support them. If I couldn’t support them, then no one could.

This caregiver’s account highlights that teachers also faced challenges in supporting their students during remote learning, but because her children were in kindergarten, they were still learning their letters and numbers, and as a result of remote learning, they often struggled to understand and complete the work on their own, thus needing her hands-on assistance.

Advocacy Strategies & Sources of Support

Participating caregivers then moved on from the multiple barriers they encountered to describe the advocacy strategies they used to help leverage support and services for themselves and their children. Most participating caregivers shared that the best advocacy strategy they utilized was themselves. As discussed above, many caregivers felt isolated by navigating their respective systems and were often assigned inadequate providers; as a result, it was up to them to do their own research and use their voices to speak on behalf of their children. Most caregivers also shared that they looked within their existing relationships to find emotional support and, on occasion, to deepen their advocating skills. About half of the participating caregivers also discussed how they intentionally used existing parent engagement structures as a tool to further their advocacy strategies.

Leveraging Skills & Expertise for Advocacy

Although many caregivers discussed how convoluted and confusing their engagement with CWS and/or SES was, they also shared how they found skills and expertise that helped them navigate their respective systems more easily and advocate for themselves and their children. Several caregivers discussed how their skills and expertise were acquired from their formal college education. As one CWS caregiver stated:

> I am also a little more educated in the system and I was finishing my bachelor's at the time that the case was open, so intellectually, *I knew how to ask questions and how to advocate* for myself and family (emphasis added).

She went on to share that her school experience prepared her to ask clarifying questions and better analyze documents. She also noted that if not for her formal training, she would have gotten lost in the systems' intricacies.

Several other college-educated caregivers also had careers in education or social services and stated that they learned to advocate due to the skills gained from their current positions. A caregiver who was a social worker in a community mental health agency shared how she learned to advocate for her children because she advocated for families in her work:

> I want to say that I became aware of [IEPs] through my job, where we help advocate for children's needs. And one of the families that I was working with… their child who was still… who was three, they got an IEP, and then that sparked the light bulb when I was like, "Wait, my child is able to, even though she hasn't

> started a school officially; as soon as they turned three years old, they're able to request an IEP through the school district." And that's what I did.

She continued, saying that at first she was not as confident speaking up during her daughter's IEP meetings, but eventually she realized nobody else would if she did not. This was a common sentiment amongst several participating caregivers.

Most parents of my study, whether college-educated or not, did online research to deepen their understanding of the CWS and/or the SES. Some shared that this independent research was invaluable because they could not depend on the system providers to guide them in the right direction. Many shared how they used their newfound knowledge to advocate for their children during IEP meetings or in situations involving their child welfare program. A caregiver preparing for her first IEP meeting explained, "Through Google, I learned a lot. Like, what do I need to ask? Like, what about it, what should I say? So, I think, you know, that that helped me and that's how I kind of prepare myself."

Caregiver Engagement as an Advocacy Strategy

Participating caregivers unanimously emphasized the crucial role of caregiver engagement in navigating the CWS and/or SES; they viewed engagement as essential for staying informed about system-related information and updates. Additionally, caregivers believed that active involvement was necessary to address the systems' potential conflicts with their children's needs. Some caregivers went beyond advocating for their own children and utilized engagement to advocate for broader systemic improvements. Overall, caregiver engagement was seen as a vital component for informed decision-making, overcoming challenges, and promoting positive change within these systems.

One caregiver, initially ignored by the SES, shared how her active engagement and persistence were crucial to getting her child services:

> It took a while for me. Actually, I never got the SSPT [student support parent team] meeting because after so many attempts to request an SSPT, it just got to the point where I wrote a letter with all my concerns and all the history that I had for my kids, for my daughter, and I requested an IEP.

This caregiver recounted that she had been active in her child's school, and although her initial request for a support plan failed, her persistent advocacy led to her daughter receiving services through an IEP.

Another caregiver shared how she needed to be actively engaged with the CWS over the course of several years in order to advocate for her son's needs and to connect him to needed services, exhibiting Yosso's (2005) concept of resistance capital through her displayed resilience in the face of adversity:

> He did receive services, but not because of the social workers in this case… they really failed him. I got him connected with different mental health agencies; we went through, like, I want to say, four or five different agencies since he was ten, to the age of 18.

Interestingly, this parent stayed engaged with the system that was not supportive of her or her child's needs.

While navigating and engaging CWS and SES, one caregiver discussed how he could not find any information about the experiences of gay parents who were engaged in foster-to-adopt programs. He shared that this lack of information and support motivated him to start a podcast detailing his experiences as a gay foster-to-adopt parent:

> I actually started a podcast around that time. Because we've had a very romantic placement. Our boys are incredible. Sure, we've had really difficult things that we've been through. But all in all, it's a very positive experience. And so, to try to encourage more folks to go down this path, we started a podcast that focused on the positive storytelling aspect of it.

This caregiver went on to discuss the importance of caregiver engagement as key to his success in navigating the CWS and SES. He shared how he joined the school's PTA while his partner joined the school board:

> The goal was to be heavily involved, so at least the teachers and principals would know our faces. Joining the District School Board, you're helping make decisions, not just for your family, but all families. He represents the foster-to-adopt children. He represents the Hispanic kids. He represents the gay community. And I hate saying this too, but he represents being a dad. And there are not many dads that are involved in school.

Another parent similarly shared how she became vice president of her child's school council because she recognized the importance of active parent engagement and would be better able to advocate for her child if staff knew who she was:

> I think even now being part of the school meetings after school, being more involved about what's happening in the school, I think has helped me, because now the principal knows who I am. But now that I'm also involved in those meetings, I was kind of more driven into be the Vice President.

This parent went on to share that being on the council had given her a platform to advocate for her child as well as the needs of parents, proving to be an excellent example of how caregivers can effectively utilize their social capital for advocacy gains.

Ultimately, many caregivers shared a desire to engage with their respective systems because they would be better positioned to advocate for their children. As one caregiver expressed, “At the end of the day, you’re kind of on your own. And you;re the only person that needs to advocate for your child.”

Leveraging Existing Relationships

Although all caregivers shared an array of challenges they experienced on their journey of navigating and engaging with their respective systems, many described how they leveraged their existing relationships amongst friends, family, and coworkers to deepen their advocacy strategies and foster support for themselves and their children.

A caregiver who was initially struggling to advocate for her child’s special education needs described how her coworker was a great source of support: “I think she was such a big support, you know, because she had already gone through that, through that experience.” She further explained that her coworker also had a child with a disability, so she was able to depend on her for both information about the process and emotional support. Similarly, another caregiver who was involved in both the CWS and the SES expressed that her friends were very supportive: “I had one specific friend that… she did have a son that was autistic. And so, you know, we would always just kind of talk about, you know, the mom issues that comes with that.” This caregiver also noted that knowing another parent of a child with a disability was wonderful because she did not feel alone in her experiences.

Participating caregivers sometimes shared that they leaned on several close relationships to successfully engage with and navigate their respective systems. As one caregiver explained, “I’m very blessed that I have his dad that helps me, his grandmother, my aunt… like, I have a lot of support. But if I didn’t have that, I know it’d be very difficult.” This caregiver also shared that a close friend was a school psychologist, so her ability to advocate for her child was a result of guidance from this friend, as well as from the support of her family: a compelling illustration of caregivers leveraging their familiar capital. Similarly, another SES caregiver shared that her sister was a classroom teacher familiar with the IEP process, and thus she was able to learn from her sister’s expertise.

One CWS caregiver shared how she leveraged her relationships with several friends who worked in the child welfare system to better understand the intricacies of the system. This led her to better understand how to advocate for services. Although many caregivers shared that they gained confidence, knowledge, and experience in learning how to advocate, many also shared that engaging these systems was demanding and they never really felt ready. As one caregiver said, “You don't actually know what it is until you’re actually in it.”

Conclusion

This chapter presents several key findings of the study. First, irrespective of the system involved, caregivers shared similar aspirations for their children. Second, navigating the child welfare and/or special education system proves to be a daunting and emotionally charged experience for caregivers. Thirdly, the caregivers of my study encountered various challenges during their journey through the CWS and SES, yet went on to employ diverse advocacy strategies and resources as a means to effectively engage with and navigate these systems.

CHAPTER FIVE: DISCUSSION

This dissertation contributes to existing research on parent engagement in the child welfare and school systems by exploring the experiences of caregivers navigating these systems in regard to the resources they found helpful, the barriers they encountered, and the advocacy strategies they utilized. Many previous studies on parent engagement have explored the topic through the lens of biological parents; this study expands on the current literature by incorporating additional caregivers' experiences, including biological and non-biological caregivers, caregivers involved in kinship care, and those involved in foster-to-adopt programs.

In this qualitative study, a total of 15 in-depth interviews were carried out with caregivers who fell into one or more categories: (a) those who had previous involvement in the child welfare system (n=4); (b) those who had a child enrolled in a special education program due to a disability (n=6); or, (c) those who had both previous involvement in the child welfare system and a child enrolled in a special education program due to a disability (n=5). The interviews of these subjects helped me find answers to the following research questions:

1) What are the experiences of caregivers navigating the child welfare system and/or the special education system?

2) What sources of support do caregivers utilize when navigating the child welfare system and/or the special education system?

3) What barriers do caregivers navigating the child welfare system and/or the special education system encounter and what advocacy strategies do they use to overcome those barriers, if any?

This final chapter provides an analysis of the research findings, drawing connections to previous studies. It also addresses the study's limitations, discusses the implications for practice, and concludes with recommendations for further research.

Connections to Prior Research

RQ1: Experiences of Caregivers Navigating the CWS and/or the SES

Research Question 1 aimed to gain a deeper understanding of the experiences of caregivers navigating the child welfare and/or special education systems. The findings suggest that their experiences were multifaceted and encompassed a range of emotions and challenges, highlighting several key stages caregivers worked through as they navigated their respective system. Initially, many caregivers experienced denial and anger as they grappled with accepting the severity of their child's disability and their own involvement in the CWS and SES. As caregivers encountered systemic barriers and inefficiencies, *frustration* and *anger* emerged, impacting their well-being and engagement with the systems. *Depression*, *isolation*, and *stress* were also common experiences, particularly when caregivers felt overwhelmed and/or lacked understanding or support. However, as caregivers progressed through each system, *acceptance* became a crucial stage wherein they acknowledged their child's disability, understood the reason for their CWS involvement, and became empowered to make informed decisions. These emotions and stages are integral parts of the caregiver experience within these systems, highlighting the complexity and depth of their journey. Caregivers who prioritized education and a better life for their children had significant levels of *aspirational capital*. These strong desires for their children often resulted in the development of *resistance capital* within these caregivers. This resistance capital empowered them to advocate for rights for them and their children, exhibit resilience, and engage these complex systems more effectively.

Emotional Toll

These findings shed light on how caregivers respond to their child’s disability and manage their emotional experience within the complex systems of child welfare and special education system. As mentioned above, denial and anger often emerged as initial reactions among caregivers when confronted with their child’s disability or engagement with the CWS. These emotions appear to serve caregivers as a defense mechanism, helping to shield them from the immediate shock and stress of a life-altering situation, in most cases either learning about their child’s diagnosis or being told they were under CWS investigation. These findings expand on work by Ho and Keiley (2003) who found denial as a common feeling experienced by caregivers with children with disabilities, but did not explore experiences of caregivers involved in multiple systems. My research revealed that denial and anger manifested in different ways such as disregarding or minimizing official diagnoses, rejecting offers for support services, or delaying necessary interventions. Understanding this stage of caregivers’ experiences is crucial because remaining stuck in denial and anger can impede their ability to seek the necessary support for their children and fully participate in the CWS and SES.

This denial and anger was frequently followed by feelings of frustration and anguish, reflecting caregivers’ struggle to cope with the emotional impact of their child’s challenges and/or their own perceived shortcomings. The process of recounting their stories and undergoing various assessments for their children was emotionally taxing, intensifying frustration and anger, consistent with earlier research findings on caregivers seeking support services (Doig et al., 2009). This study goes beyond existing research by providing insights into the experiences of caregivers who are simultaneously seeking and receiving support services from multiple systems.

This research contributes to the field by demonstrating how depression and isolation often accompany the caregiving journey, especially when the caregivers feel overwhelmed or perceives a lack of understanding and support from their environment. Prior research has revealed that navigating intricate systems and encountering obstacles can worsen mental health conditions, leading to feelings of depression (Benson & Karlof, 2009; Kelly, 2021). In line with feelings of depression, caregivers in this study often expressed a sense of being overwhelmed and isolated, struggling to find support, understanding, and validation within the systems. The lack of recognition of their mental health needs by professionals further contributed to their feelings of isolation and hampered their ability to seek assistance, aligning with prior studies on the emotional experiences of caregivers (Baik & Jun, 2021; Merritt, 2021).

Stress was another prevalent emotional experience among caregivers, reinforcing the findings of Benson and Karlof (2009). Balancing the day-to-day care of their children with disabilities, coordinating appointments and therapies, and managing the demands of the systems created immense stress for all involved. Conflicting responsibilities, pressure to meet system expectations, and a lack of time for self-care all contributed to heightened stress levels amongst caregivers.

Acceptance

However, over time, many of the participating caregivers also reported a journey towards acceptance. While the process of acceptance varied depending on the specific context and type of involvement, it generally involved recognizing and embracing the processes, protocols, and expectations set forth by the systems. Caregivers gradually understood the need for realistic expectations, adjusted their aspirations, and found positive outcomes within the systems. Acceptance also involved personal growth and a shift in perspective as caregivers learned to trust the process, prioritize empathy, and focus on their own well-being, consistent with existing literature on caregiver resilience and adaptation (Gayatri & Irawaty, 2022; Lietz & Strength, 2011).

RQ2: Sources of Support Caregivers Utilize when Navigating the CWS and/or the SES

Research Question 2 focused on identifying the most effective sources of support utilized by caregivers when navigating the child welfare and/or the special education systems, the goal being to gain a deeper understanding of the types of support that were most helpful. Two crucial sources of support that have a significant impact on caregivers' experiences were revealed: 1) leveraging existing relationships, such as close friends and family members, played a vital role; and, 2) realizing the caregivers' own knowledge, skills, and expertise were instrumental in effectively engaging with professionals and making well-informed decisions. These findings highlight the importance of *familial and social capital* in navigating the complex systems of child welfare and special education.

Leveraging Existing Relationships

Close friends and family members served as a crucial source of support for caregivers, offering emotional support, practical assistance, and acting as a counterbalance to the emotional turmoil presented by system engagement. By leveraging these sources of support, participating caregivers empowered themselves to advocate for their children's needs and overcame many of the challenges they encountered. This important finding showcases the resourcefulness and strength of caregivers in accessing the support they require, especially in situations where they often lack assistance from support systems that are supposed to help them. Additionally, the journey of navigating the CWS and SES can be emotionally draining and isolating. Having a network of supportive individuals who share similar experiences helped alleviate the stress, anxiety, and isolation caregivers faced. While previous studies have explored the benefits of support systems (Jackson, 2011; Larios & Zetlin, 2022), this study not only aligns with prior research but also enhances understanding of caregiver experiences in circumstances where supportive relationships were difficult to access or were interrupted due to external factors beyond the caregivers' control, such as the COVID-19 pandemic.

Leverage Existing Knowledge, Skills & Expertise

This study highlighted the important role of caregivers' knowledge and experience in navigating complex systems. Caregivers who possessed skills like formal education or professional expertise were able to effectively interact with professionals, analyze documents, ask pertinent questions, and make well-informed decisions. While having highly-educated and skilled caregivers was advantageous in this study, it also underscored the complexity of the CWS and SES systems. Furthermore, it is important to recognize that not all caregivers possessed these qualifications. For caregivers who were not highly-educated or skilled, the findings reveal the challenges they faced including, but not limited to, difficulty in analyzing complex documents and having limited access to information and support networks. The complexity of these two systems proved to be overwhelming to my study's participants, despite their education and/or work status; however, those with higher levels of education and skill were sometimes better able to navigate their system(s) effectively just as were those caregivers who had friends with experience within the system(s). This significant point highlights the need for additional support and resources for caregivers who lack formal education and/or professional training, though overall, the findings prove all caregivers encountered a lack of system support.

The importance of recognizing and valuing caregivers' skills and expertise cannot be overstated. Professionals and service providers within the CWS and SES can greatly benefit from the knowledge and insights that caregivers bring to the table (Burke & Goldman, 2018; Trainor, 2010). Moreover, when caregivers are equipped with necessary skills and expertise, they become empowered advocates for their children, working alongside professionals to navigate the systems and ensure best outcomes. By acknowledging and supporting caregivers' skills, service professionals can work in tandem with caregivers to create a more inclusive, informed, and responsive system, one that meets the unique needs of children with disabilities and promotes their overall well-being.

RQ3: Barriers Encountered in CWS and SES & Advocacy Strategies to Overcome Them

Research Question 3 examined the experiences of caregivers navigating the CWS and/or the SES, focusing on the barriers they encountered and the advocacy strategies they employed to overcome these challenges. Participating caregivers faced significant barriers with service providers, which resulted in a lack of support, communication gaps, and delays in accessing essential services. This phenomenon revealed that navigational capital is instrumental for caregivers in their journeys. Caregivers who took it upon themselves to develop knowledge and skills to navigate the complexities of the systems familiarized themselves with policies, procedures, and available resources so to advocate effectively for their children.

The COVID-19 pandemic further exacerbated these difficult barriers, though all caregivers in this study shared that they continued to seek support during that time. Their deep aspirations for their children's future remained as a constant, and served as a profound motivator for caregivers' commitment to advocate for their children. Caregivers recognized the importance of active engagement and self-advocacy in navigating these complex systems.

Lack of Support & Communication

A significant barrier was recognized across participants' interviews: the lack of support and communication from CWS and SES service providers; this issue was exacerbated for caregivers navigating both systems simultaneously. Caregivers expressed frustration and dissatisfaction with the support received from social workers, therapists, and other service providers, aligning with existing literature on caregiver challenges (Maiter et al., 2006; Merritt, 2020). Further, the lack of communication between these two systems left caregivers with dual engagement alone in figuring out how to navigate each system. As a result, caregivers felt neglected, overwhelmed, and unsupported. This lack of responsiveness and attention from service providers is concerning, particularly considering that caregivers are already dealing with their own internal emotional stages. This emotional burden sometimes made it difficult for caregivers to engage effectively, potentially causing further delays in services or leading them to be perceived as defensive or uncooperative clients.

Furthermore, the experiences of the study's caregivers underscored the pressing need for improved communication between caregivers and professionals within both the child welfare and special education systems. Timely and clear communication was identified as a crucial factor in ensuring that caregivers received the necessary services and support for their children. Caregivers expressed the importance of being kept informed about their children's progress, upcoming appointments, and any changes in the care plan and/or IEP, yet cited the lack of this information as a key factor in their frustrations with each system. Caregivers felt that teachers, social workers, and other service providers were either ill-equipped or reluctant to address their children's specific needs. For example, they reported a lack of understanding and familiarity with their children's unique challenges and requirements, leading to frustration and concerns about the quality of education and support their children were receiving, reinforcing the findings of previous studies (Zagona et al., 2019). This study discovered that as caregivers familiarized themselves with their respective systems, often with the help of close friends and family, they became more empowered to address challenges posed by service providers; previous studies have not addressed this point directly. Caregivers in this study actively sought changes in providers for their children or challenged the services they received, advocating for more support.

Delays & Disruptions

Caregivers in this study frequently encountered frustrating delays and disruptions within the CWS and SES, often involving extended waiting periods for assessments and hindering timely intervention planning. Additionally, there were delays in accessing critical therapeutic services, such as counseling or speech therapy. Findings emphasize the potential negative consequences of such delays on a child's development and well-being as their needs may go unaddressed during these waiting periods (Kelly, 2021); additional harmful impacts are felt within family dynamics.

In addition to delays, caregivers also experienced disruptions in the availability of services and support. Temporary closures of agencies and organizations responsible for providing crucial services, such as child welfare support or special education programming, further exacerbated the difficulties faced by caregivers. These closures, which might have been due to staffing shortages, budgetary constraints, or unforeseen circumstances like the COVID-19 pandemic, left caregivers in a state of uncertainty and thus hindered their ability to access the necessary resources to support their children effectively. Consistent with previous studies (Frederick et al., 2020; Goldberg et al., 2021), this phenomenon emphasizes the systemic challenges caregivers encounter in accessing essential services within the CWS and SES. The delays and disruptions encountered by caregivers not only underscores the individual challenges they face, but highlights systemic inefficiencies and gaps in service provision.

Of significance is how the COVID-19 pandemic contributed to the delays and disruptions participating caregivers faced. The pandemic resulted in extended court dates, further elongating the already lengthy legal processes involved in CWS. This disruption exacerbated caregivers' anxiety and frustration, as the prolonged court proceedings intensified uncertainty and impeded their ability to make necessary decisions and/or take appropriate action regarding their children's well-being. My findings align with previous studies that highlight the detrimental effects of extended legal processes on caregivers' well-being and child outcomes (Capps et al., 2015; Vesely et al., 2019).

Additional Pandemic Challenges

The shift to virtual service provision presented significant challenges for both caregivers and their SES children. Previous studies have also found similar challenges experienced by caregivers as they engaged with virtual platforms (Morgan, 2022; Roy et al., 2022). Caregivers expressed dissatisfaction with remote learning, perceiving it as less effective than in-person instruction. The absence of face-to-face interaction and personalized attention posed obstacles to delivering appropriate support to children with special education needs. Further, caregivers highlighted a significant obstacle in the form of inadequate technological assistance, especially for younger children who lacked the necessary technological skills and academic knowledge to effectively participate in virtual schooling. This observation aligns with the conclusions drawn in the study conducted by Morgan (2022), which illustrated how the digital divide further marginalized these children, hindering their ability to fully engage in remote learning and receive the academic support they required. The findings of this dissertation reinforce the existing literature on the challenges of virtual learning and the disparities it creates (Oster et al., 2021).

Moreover, the pandemic presented additional difficulties for caregivers who had work responsibilities. The challenge of juggling work responsibilities alongside increased caregiving duties due to school closures and remote learning proved to be quite daunting. Caregivers felt overwhelmed and strained as they struggled to fulfill both their professional and caregiving obligations (see also Chung et al., 2020; Garthus-Niegel et al., 2022). Caregivers struggled to provide the necessary academic support and supervision for their children while fulfilling their work commitments.

Caregiver Advocacy & Engagement

This study found that caregivers in the CWS and SES recognized the importance of advocating for their children and thus actively looked for ways participate in decision-making processes. Their persistent advocacy efforts, such as writing letters, requesting additional services, and joining educational governance structures, showcased their determination to ensure that their children received necessary support. Overall, this study revealed that caregivers recognized the significance of self-advocacy and active engagement in navigating the CWS and SES, consistent with previous research (Bacon & Causton-Theoharis, 2013; Burke et al., 2018; Trainor, 2010). This self-recognition by caregivers underscores the need for self-advocacy and active navigation of the systems. Research has shown that active engagement through self-advocacy is crucial for caregivers to assert their rights and make informed choices on behalf of their children (Rehm et al., 2013). Such caregiver engagement not only benefits their own children, but has the potential to drive systemic change (Rossetti et al., 2021).

Study Limitations

One limitation of this study relates to the sampling process which may have favored participants who held specific viewpoints and were motivated to share their grievances. This potential bias in participant selection could have influenced the themes that emerged from the study, potentially skewing the representation of certain perspectives or experiences. If the participant selection process favored individuals with specific characteristics or backgrounds, the resulting themes may be more reflective of those particular groups. Conversely, if certain groups or individuals were inadvertently excluded from the selection process, their unique experiences and perspectives would be absent from the analysis. This could lead to biased or incomplete themes, potentially distorting the interpretation of the data.

Many of the caregivers in this study had a college education and a connection to the CASSW, thus suggesting their greater access to resources, knowledge, and social networks that potentially enhanced their ability to advocate effectively. Their educational backgrounds might have equipped them with critical thinking skills, research proficiency, and an understanding of policies and procedures, enabling them to navigate the complex SES system more adeptly. It is essential to consider the potential biases introduced by this specific demographic composition. The overrepresentation of caregivers with college education and CASSW affiliation could lead to an unintentional exclusion of perspectives from caregivers with different educational backgrounds and/or limited access to support networks. As a result, the findings of this study may not fully capture the experiences and challenges faced by a more diverse range of caregivers.

Another limitation of this study is the potential lack of disclosure and/or withholding of experiences due to participants' vulnerability. As the participants in this study were involved with historically marginalizing systems, such as the CWS, there was a risk that fear and/or shame could have hindered them from providing a comprehensive account of their experiences. This guardedness was particularly evident when discussing their CWS involvement as many of these participants provided only minimal details or attributed their involvement to misunderstandings or mistakes. As a researcher, my positionality could have affected how participants shared their experiences with me. Factors like power dynamics, how well participants thought I understood them, and how I talked to them could have created additional limitations.

Furthermore, the study primarily focused on the experiences of caregivers and did not incorporate the viewpoints of their children with disabilities or who were engaged in the CWS, nor did it include viewpoints of system service providers, therefore, there is no way to cross-validate any information provided by the participants. The study did not examine the intersectionality of caregivers' identities and how they might have affected their experiences when navigating the CWS and/or SES. Exploring these experiences would provide a deeper understanding of the unique challenges faced by caregivers from diverse backgrounds and shed light on potential disparities and inequities within these systems. By considering intersectionality, we can better comprehend the interplay of race, ethnicity, gender, socioeconomic status, sexuality, and disabilities and how they shape caregivers' experiences and outcomes.

Implications & Recommendations

Culturally Sensitive & Trauma-Informed Comprehensive Services

The main goal of this study was to give a voice to caregivers who are involved in complex systems that often overlook their valuable insights and experiences. From the findings, it is evident that both school and child welfare systems can better support caregivers by providing culturally-sensitive and trauma-informed comprehensive services. These comprehensive services should include assistance with understanding the system, accessing resources, and navigating the various processes involved. Culturally-sensitive and trauma-informed comprehensive services can have a significant impact on caregivers and their ability to navigate the CWS and SES. In this study, caregivers encountered numerous obstacles and stressors when accessing services and advocating for their child, including feeling overwhelmed, stressed, frustrated, and depressed. Providing culturally-sensitive and trauma-informed services could also help reduce the stress and anxiety experienced by caregivers and improve their ability to advocate for their children.

Interagency Collaboration

A crucial suggestion for enhancing practice is to improve collaboration between the CWS and SES. Participating caregivers who were involved in both systems frequently discussed the challenges they encountered while attempting to obtain educational rights for their children. In such situations, caregivers reported that although the school had identified the need for special education services for their children, they were unable to provide those services due to the biological parents retaining educational rights, which prevented foster parents from making any decisions. Improving collaboration between the CWS and SES is an essential step towards improving outcomes for children and families. By ensuring timely and coordinated services, caregivers can receive targeted and more effective support that addresses the specific needs of their children. Strengthening collaboration between these systems can be done through the use of interagency agreements, memoranda of understanding, and/or regular meetings. Cross-training between child welfare and special education providers can also help build understanding and facilitate communication. Finally, a wraparound approach involving both systems can provide more comprehensive and coordinated services to children and families by leveraging their unique expertise and resources.

Enhanced Resources & Access to Information

This study revealed that caregivers play a critical role in advocating for the needs of their children immersed in the CWS and SES; thus, it is essential to provide them with the necessary support and resources so to advocate effectively. To achieve this, one effective approach is to offer in-house training and resources on advocacy skills and strategies, while also connecting caregivers with external advocacy organizations that provide additional support. School systems can utilize existing personnel, such as parent coordinators and school social workers, to provide trainings and resources directly to caregivers. Similarly, the CWS can tap into its network of community partners to offer supplementary trainings and support for caregivers. By leveraging these resources, both school systems and the CWS can enhance caregivers' knowledge and empower them to navigate their roles more effectively. It is important for education and child welfare systems to assess the clarity and accessibility of the information they provide to caregivers, seeking feedback to ensure that the information is comprehensive, understandable, and readily available. By actively promoting caregiver advocacy training and evaluating the effectiveness of information dissemination, these systems can better support caregivers in their vital role.

Several participants in this study spoke about the difficulties experienced by not fully understanding the logistics of their child's special education or not being able to find resources when involved in the CWS. In addition to supporting caregivers in advocating for their children, it is also crucial that the CWS increase caregivers' access to information. Caregivers need clear and concise information about their rights and the resources available to them. This information should be provided in multiple formats and languages to ensure that all caregivers have maximum access. By providing comprehensive information, caregivers can better understand the system and their children's rights, which can empower them to make informed decisions.

Consideration of Abolitionist Movements

There is an increasing number of individuals advocating for the abolition of the child welfare and special education systems (Dettlaff et al., 2020; Johnson, 2021). They acknowledge the historical harm caused to communities of Color by these systems and their continued detrimental effects. The child welfare abolitionist movement emphasizes the negative consequences of interventions, specifically the removal of children from their families, arguing that such actions often result in more harm than good (Sankaran et al., 2018). Disability activists often assert that disability is a natural aspect of human diversity and should not be perceived as a disorder or deficit (Johnson, 2021). Caregivers in this study expressed and recounted diverse experiences, illustrating the harmful effects of the CWS and SES on themselves and their children. Consequently, they sought solace and assistance from alternative sources such as friends, family, and other supportive networks, even though these networks were not officially recognized or supported by the prevailing systems. Given the call for the abolition of the child welfare and special education systems, and their lack of support in many cases, it is imperative for research to explore and evaluate alternative approaches that prioritize community-based support and mutual empowerment. Such research should examine innovative models that focus on family preservation, early intervention, and wraparound services so to address the needs of vulnerable children and families. This includes studying the effectiveness of preventive measures such as strengthening social support networks and providing culturally-competent interventions that mitigate the disproportionate impact on communities of Color.

Recommendations for Future Research

Several recommendations for future research emerged from this study. First, future research should prioritize an in-depth examination of the intersectionality between the CWS and the SES, with a particular focus on race, poverty, disability, and other relevant factors. Both systems have faced accusations of racism, lack of support, and potential harm, highlighting the urgent need for comprehensive investigations into how these systems either facilitate or hinder individuals in navigating them effectively. By exploring the intersectional dynamics within these systems, researchers can uncover the nuanced ways in which race, poverty, disability, and other intersecting identities shape individuals’ experiences and outcomes. This research should strive to understand the structural barriers and biases that exist within the systems, as well as the ways in which these barriers disproportionately impact marginalized communities and their caregivers.

This dissertation focuses primarily on the experiences of caregivers, but it would be valuable to explore the experiences of children with disabilities who are in the foster care system. So doing would contribute to a more comprehensive understanding of the intersection of disability and child welfare. Due to the delicate circumstances that these children find themselves in, there is limited research examining their experiences, therefore, future research could explore their unique challenges and learn firsthand what these children need within both systems.

During the study, participants highlighted the advantages of collaborating with nonprofit organizations, often citing better experiences and higher-quality services as compared to traditional child welfare or school systems. Consequently, it would be valuable for future research to investigate the specific forms of support provided by these non-profit organizations and identify ways to enhance collaboration and coordination between community organizations, the CWS, and the SES in supporting caregivers and children.

Caregivers in this study expressed powerful emotions about interacting with and navigating the CWS and/or SES, and pinpointed different forms of support that were beneficial to them. Future research could investigate the impact of specific caregiver support programs on various outcomes related to the well-being of both caregivers and children with disabilities. For instance, future research could explore how caregiver support programs impact caregiver mental health, coping mechanisms, and stress levels. This research could employ various measures, such as standardized scales for depression, anxiety, and stress, to determine the effectiveness of support programs in reducing caregiver stress levels and improving mental health outcomes.

Conclusion

This dissertation provides valuable insights into the advocacy strategies and resources utilized by caregivers navigating the child welfare and special education systems. It underscores the importance of self-advocacy, research, skills and expertise, active engagement, and support networks in empowering caregivers to effectively advocate for their children. Findings contribute to the existing knowledge on caregiver advocacy and provide recommendations for practitioners and policymakers to better support caregivers, thus improving outcomes for children in these systems. By addressing these findings, practitioners and policymakers can better support caregivers in advocating for their children’s needs, improve collaboration between the CWS and SES, and enhance outcomes for children in these systems. Recognizing and supporting caregivers as advocates and providing them with the necessary tools and resources would create more inclusive and supportive systems that prioritize the well-being and success of children with disabilities.

APPENDIX A

Interview Protocol

Thank you for taking the time to meet with me today. I am completing dissertation research for my educational doctoral program at UCLA. I am interested in understanding the experiences of parents with children with disabilities and their experiences navigating the child welfare system and the school system. I am also interested in learning the barriers and supports that mothers experience as they navigate/d the CWS and the school's special education program..I will be asking you a series of open-ended questions about your experiences, this interview will take approximately an hour. In order to be fully present and attentive to your responses, I will be recording the interview rather than taking detailed notes. You may request to skip a question or stop the interview at any time. Everything we discuss in these interviews is confidential, so please feel free to speak openly and give specific examples. The data collected in this interview will be transcribed, analyzed, and potentially included in a dissertation. Individual and institutional identifying information will remain confidential. Do you have any questions before we begin? (Pause for questions.) Are you okay with me recording this session? (Pause for affirmation). Great, let's begin.

Opening Questions

1. Tell me a little about your child- (age, grade in school, what your child likes to do etc.)
2. What do you like to do for fun with your child?
3. What are your aspirations for your child?

If Applicable.

Core Questions

1. Can you describe your experiences of being involved with the child welfare system?

2. What were your initial thoughts and feelings when you found out you were involved with the CWS?
3. What was difficult about navigating the child welfare system?
    a. Who or what helped you navigate or understand the child welfare system?
    b. Did you understand your legal rights in this process of being involved in the CWS?
    c. What do you know now that you wished you knew during your involvement with CWS that would have made this process better for you?
4. What would you change about the child welfare system to make it easier for parents to navigate the process?

If Applicable.

NOW LET'S SWITCH GEARS. We talked about CWS now let's talk about your child’s special education program.

5. Can you describe your experiences of being involved with your child’s special education program at school?
6. What kind of disability does your child have, per their IEP?
7. How did you learn or know that your child needed services and support?
8. What kinds of challenges does your child experience?
    a. How has the complexity evolved over time, have they gotten better or worse?
9. What services has your child been given?
10. Is there any services that your child is not currently receiving that you would like them to receive?
11. How have you advocated for your child throughout the process

12. Who or what helped you navigate or understand the school's special education program?
13. What was or currently is difficult about navigating your child's special education program?
14. Tell me about your role as a caregiver in the IEP process.
15. Have you felt like you were included in the decision-making?
16. Did you know your rights as a caregiver in this IEP process?
17. What do you know now that you wished you knew during your initial involvement with your child's special education program that would have made it easier for you to understand or navigate?
18. What would you change about the school's special education program to make it easier process for you or other parents with children with disabilities?

If Applicable.

I will now ask you two questions that incorporate both your experiences in the CWS and your child's special education program.

1. What things did you have to do to make sure your child's needs were met in the CWS and special education program at their school?
2. What has been your overall experiences navigating both your child's special education program and the Child Welfare System?

Wrap Up

1. Is there anything you would like to add?

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