



# CAREGIVERS EXPERIENCES RAISING, ENGAGING, AND INVOLVING CHILDREN WITH INVISIBLE DISABILITIES

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## ABSTRACT

The experiences of caregivers navigating through the K-12 school system as their children with invisible disabilities move toward high school graduation are multifaceted. A qualitative study examined the experiences caregivers were having or not having at Central High School (CHS), a traditional high school within the Public School (PS) district, located in a mid-western city in the United States. Questions posed revealed the encounters of caregivers rearing their children with invisible disabilities. Conceptually, the study was guided by the ecologies of parental engagement (EPE) framework. Data was collected through semi-structured interviews, member checking, a follow-up interview, and document analysis to provide thorough descriptions of the caregiver' experiences. Four participants were selected for the study based on the following criteria: their children were currently enrolled at CHS, in the 11<sup>th</sup> or 12<sup>th</sup> grade, and had been diagnosed with an invisible disability. A line-by-line analysis of participants' responses uncovered common themes. The results of this study contribute to the implementation of progressive changes by providing information to parents and school staff on how to collaborate more effectively with each other for the advancement of children with invisible disabilities.

**KEYWORDS:** Invisible Disabilities, Parental Involvement, Collaborative Evaluation

## INTRODUCTION

According to the Invisible Disabilities Association's (2019) website, the definition of an invisible disability is a "physical, mental or neurological condition that limits a person's movements, senses, or activities that is invisible to an onlooker" ("What Is an Invisible Disability?" para.1). Caregivers rearing children with invisible disabilities may encounter challenges with school staff as they help their children navigate through the K-12 system to high school graduation. Since the child's disability is hidden or invisible, school staff may be reluctant to believe the child has a disability that is legally protected (Koro-Ljungberg, Bussing, Wilder, & Gary, 2011). Though a complete list is difficult to compile due to the considerable number of conditions classified as invisible disabilities, attention deficit hyperactivity disorder (ADHD) and dyslexia are two commonly known disabilities that are classified as invisible disabilities. Even though these disabilities are "invisible," they have a visible impact not just on the people who have the condition, but also on the individuals raising them. Relationships between parents and school staff can be strained when misunderstandings occur around invisible disabilities.

## PURPOSE OF STUDY

The purpose of the study was to examine the experiences of caregivers were having or not having at Central High School (CHS), a high school within the Public School, (PS) district as they navigated their children with hidden disabilities through the K-12 system to high school graduation. The hope was that the findings of the case study would provide insight on how caregivers would like to receive information, supports, and resources from PS district staff. In addition, this study was designed to reveal what caregivers felt was lacking in their experiences at CHS. The major research question that the study sought to answer were as follows: Do cultural/social differences between caregivers and staff influence parents involvement and

engagement in the school? How? If so in what ways? The goals of the study were: (a) to bring to light the obstacles that caregivers' experienced while their children with hidden disabilities moved to graduation from high school; (b) to see how caregiver involvement and engagement or the hinderance of parental involvement and engagement affected parental experiences in their child's navigation to high school graduation, particularly during the late high school years; (c) to provide caregivers navigating their children with hidden disabilities a voice to better secure the needs of caregivers on behalf of their children; and (d) provide educators from urban school settings (more specifically PS/CHS) with ideas about how to partner and assist caregivers navigating their children with invisible disabilities to bring about a smoother path towards high school graduation.

## Conceptual Framework

The case study utilized the ecologies of parental engagement (EPE) framework to analyze the interaction between caregivers and school staff as children with hidden disabilities move through the K-12 educational system. Researchers Barton et al. (2004) developed the framework to offer an understanding regarding what parents engage in and how they manage to do so within urban school settings. Parental engagement is also connected to activity networks such as school, home, and other places parents choose to engage in their child's education. Parental experiences and their actions are taken into consideration within this framework. (Barton et al., 2004).

Unlike other frameworks based on parental engagement (e.g., Epstein, 2009), this framework seeks to understand parental engagement based on space and capital, not just activities that parents participate in within urban school districts. Space is defined as schools, home, and community areas, while capital is defined as human, social, and material (Barton et al., 2004). We

disputed the notion that capital is merely financial. Parents can implement other types of capital (e.g., social capital) to place themselves within spaces to engage and be involved in their child's education.

The EPE framework seeks to understand how parents utilize resources within their child's school to situate themselves to influence the school and their child's education. Culture, language, and social class are also possible factors that potentially hinder parents' forming a presence within schools. Parental engagement is more than outcomes. The EPE framework attempts to understand relationships and actions between individuals within the school setting (Means, LaPlante, & Dyce, 2015). The goal of parent engagement is to create diverse and multiple opportunities for parents to secure valuable means to participate in their child's school life. The EPE framework identifies the differences between parent involvement, what parents do, versus parent engagement, *what parents are included in* (Barton et al., 2004). Furthermore, it is important to provide a more detailed explanation of parent engagement, which is the cooperative relationship between parents and school staff that many scholars suggest positively benefits children. According to Barton et al., (2004), "We use the word engagement to expand our understanding of involvement to also include parents' orientations to the world and how those orientations frame things they do" (p. 4). The EPE framework offers an analytical viewpoint to investigate the activities that parents choose to engage in by considering the act of engagement as a collaborating process instead of merely partaking in traditional school settings (Means et al., 2015). Another unique element to the EPE framework is the emphasis on parent involvement in urban elementary schools (Barton et al., 2004). The EPE framework recognizes the reality that low-income parents' lives often determine the various forms of involvement that they can engage in versus their middle-class Caucasian parental counterparts. We utilized the EPE framework as a lens for the study because of interest in learning more about the involvement/engagement experiences of caregivers as their children with invisible disabilities navigated the K-12 school system. This framework supported the study because it considered caregiver experiences and their interactions with educators in urban schools.

An additional important component of the EPE framework is that it was constructed under the cultural-historical activity theory (Barton et al., 2004). Social organizations (e.g., schools and community-based organizations) are based on cultural values. If individuals do not come from the same cultural backgrounds, misunderstandings can occur between them (Barton et al., 2004; Blok et al., 2007; Lareau, 2003; Hill & Taylor, 2004; Pena, 2000). Parents and school staff may experience cultural disconnects regarding how to best support children with hidden disabilities. A cultural disconnect may happen when individuals from different cultures interact particularly in school settings (Koro-Ljungberg et al., 2011; Hill & Taylor, 2004; Reynolds, 2010; Westling, 1996). Cultural disconnections are common when teachers and students come from different cultural backgrounds (Koro-Ljungberg et al., 2011). Other factors (e.g., race, ethnic, linguistic, religious, and economics) may contribute to cultural disconnects (Tatum, 1992; Ladson-Billings, 1995). The lack of parental involvement and engagement makes it challenging for a caregiver who is navigating a child with invisible disabilities to stay informed about his or her child's educational progress.

When caregivers and school staff are not on the same page in regard to involvement and engagement various messages can be

sent. For instance, individuals who are not positioned equally (marginalized parents) do not receive the same type of benefits with social organizations (schools); (Barton et al., 2004). School staff were the experts and parents had little say in their child's education. When school staff hesitated to involve or engage them in their child's learning process, parents were marginalized and they did not openly express the needs of their children, (Lightfoot, 1981; Reynolds & Belvin, 2009).

Another message sent to caregivers was that their presence at schools is not wanted. Caregivers were not invited to engage in the school setting or in the goal setting process for their children (Lindsay & Dockrell, 2004; Reynolds & Belvin, 2009). Research has found that neither parent involvement nor engagement (Reynolds, 2010) is welcomed by school staff. Caregiver invitations to come into schools are rare unless there is an issue with the child particularly regarding the child's behavior (Hoover-Dempsey et al., 2005; Hoover-Dempsey & Sandler, 1995; Pena, 2000). Parents may not be welcomed or invited by school staff because these employees wish to avoid extra responsibility. Engaging with parents usually places additional accountability on school staff (Blok, Peetsma, & Roede, 2007; Lightfoot, 1981; Reynolds & Belvin, 2009). School staff may also hesitate to invite caregivers into classroom spaces due to their own insecurities regarding how to involve and engage parents (Pena, 2000). If caregivers were aware of their rights and the power that goes along with that knowledge and familiar with school policies, school staff would be overloaded with work and burdened (Pena, 2000; Reynolds & Belvin, 2009). The present power dynamic between school staff and caregivers has caregivers generally conforming to recommendations levied by school staff without backlash. School staff do not always want to give up the power that they have over caregivers. The system is currently set up for schools to have the power and for caregivers to go along with their children's being provided with whatever assistance the school staff deems appropriate (Lightfoot, 1981). School staff often seek to avoid being held accountable to provide services and accommodations for children or to be inconvenienced by engaging with caregivers. The lack of school staff willingness to partner with caregivers hinders them from obtaining services and support for their children (Blok et al., 2007; Lightfoot, 1981; Reynolds & Belvin, 2009).

Marginalized caregivers must continue to empower their children and themselves to ensure that their children's needs are being met. Caregivers should also work toward conveying messages that, despite being from marginalized populations, children who have support and guidance are capable of being successful in environments where they are set up to fail (Lightfoot, 1981; Reynolds, 2010). Marginalized caregivers who are navigating children with invisible disabilities through the K-12 system may potentially face at least two issues when attempting to partner with school staff- cultural/social differences and difficulty obtaining services and support for their child.

### Parental Involvement and Engagement

Investigating caregiver experiences within the K-12 educational system is important to the well-being of all children in schools but is particularly crucial when it comes to students with special needs. There is a lack of literature on caregiver experiences as their children with hidden disabilities navigate through the K-12 system to graduation. More research in this area may position caregivers to be valuable players in their child's education and caregivers and school staff interact with each other to bring about partnerships based on mutual respect. This research is important because the practice of not involving/engaging

parents in their child's educational journey is not working. Collaborative relationships between parents and school staff may steer research in the right direction to allow for parents to be involved and engaged in their child's education.

### **Caregivers: Why Are Their Experiences Important in Their Child's Education?**

Whether a child has a disability or not, it is hard to conceive that caregivers are not viewed as stakeholders in the child's education (Lindsay & Dockrell, 2004; Thwala, Ntinda, & Hlanze, 2015). Caregiver experiences are critical and should be taken into consideration (Westling, 1996). Marginalized caregivers often have a difficult time connecting with school staff in order to participate and be involved and engaged in their child's educational process (Chavkin, 1989). Caregivers have knowledge of their child's condition along with their child's gifts and shortcomings which could possibly provide valuable information that could contribute to the child's educational success (high school graduation); (Lindsay & Dockrell, 2004; Thwala et al., 2015).

When caregivers have a hard time fitting into their child's educational process, a power struggle can ensue between the caregiver and the school staff. This power struggle is often seen in urban rather than suburban schools (Hill & Taylor, 2004; Lightfoot, 1981; Lindsay & Dockrell, 2004). This struggle implies that marginalized caregivers living in urban settings have a more difficult time connecting with school staff than their counterparts living in suburban settings. These power struggles also create unclear boundaries between caregivers and school staff. This idea was further emphasized by Lightfoot (1981): "The struggles for clarity and boundary settings are waged daily as parents and teachers argue (silently and resentfully) about who should be in control of the child's life in school" (Lightfoot, 1981, p. 98). Investigating caregiver experiences within the K-12 educational system is important to the well-being of all children in schools but is particularly crucial when it comes to students with special needs.

### **Parental Involvement and Engagement at the Secondary Level**

Parental involvement at the secondary level is important and needed (Carpenter et al., 2016; Hall & Quinn, 2014; Hoover-Dempsey & Sandler, 1995). Once students move from elementary to secondary education, parental involvement and engagement changes (Carpenter et al., 2016; Lindsay & Dockrell, 2004). Even though the child is getting older, caregivers still want and need to be involved to ensure that their child's educational needs are met. These changes are attributed to the increase in the number of teachers that caregivers must interact with (Carpenter et al., 2016; Koro-Ljungberg et al., 2011). Teachers are assigned to more students at the secondary level (Carpenter et al., 2016). In turn, opportunities for caregivers and teachers to interact with each other formally and informally decline (Carpenter et al., 2016; Hill & Taylor, 2004). Caregivers proclaim the need to be actively involved with the professionals working with their children due to the fact their interaction may have potential influence on their child's future (Prezant & Marshak, 2006).

### **Barriers to Parental Involvement and Engagement**

Caregivers navigating their children with hidden disabilities in secondary schools encountered barriers if school staff did not adjust their thinking to believe that parental involvement and engagement are important factors for a child's educational success. There were several themes that surfaced in the literature regarding the topic of barriers to parental involvement and

engagement described in the research. The themes presented here are not a complete list of barriers but the ones that were often documented in the literature. Some of the themes that are presented hindered parental participation in their child's education with hidden disabilities. Other themes spoke to opportunities created for to personally receive validation that their involvement and engagement was meaningful not only to their child, but also for their own growth and development.

### **Communication.**

There are many areas or dimensions of communication that caregivers of children with hidden disabilities feel are barriers to their involvement and engagement in their child's educational progression towards high school graduation. Research shows that caregivers who have children at the secondary level feel as though communication between them and school is still necessary. Caregivers concluded they were often frustrated with the exchanges that took place between them and school staff (Carpenter et al., 2016). Some of caregivers' frustration came from not receiving communications in a timely manner regarding events and activities that are scheduled at the school (Baker et al., 2016). Caregivers also requested more communication from teachers, particularly pertaining to academic and disciplinary infractions.

### **Technology.**

Technology, such as computers and cell phones, may be useful ways of receiving and sending vital information. But, school staff need to be conscious that some caregivers may not have access to a computer with internet access or cell phones that are compatible with school technology to receive information about their child's progress (Baker et al., 2016; Bardroff-Zieger & Tan, 2012). In addition, school staff should not take for granted that caregivers are already trained to utilize technology (Bardroff-Zieger & Tan, 2012). Caregivers proclaimed that they preferred more traditional forms of communication with school staff (e.g., phone calls, face-to-face meetings) to discuss their child's academic progress and major discipline issues (Bardroff-Zieger & Tan, 2012; Epstein, 1985; Hall & Quinn, 2014).

### **Caregiver work schedules.**

Caregivers who work second or third shift have fewer options for involvement in student activities. Caregivers expressed that it would be helpful to have different meeting times for events to provide them with opportunities to engage (Baker et al., 2016; Hall & Quinn, 2014). Caregivers conveyed a genuine desire to be supportive to their children but at the same time acknowledged that they must make a living and provide for their children. Unfortunately, work schedules and financial commitments may impact the caregiver's involvement in school activities (Hall & Quinn, 2014; Hoover-Dempsey & Sandler, 1995).

### **Caregivers' childhood experiences.**

Another barrier that surfaced in the literature was caregivers' past school experiences from their childhood. School staff may assume if a caregivers does not participate in school activities that they are uninterested in their child's education. Memories of mistreatment and trauma that the caregiver experienced in their own childhood when they attended school may be the real reason they are reluctant to be involved and engaged in their child's education (Baker et al., 2016; Hill & Taylor, 2004).

### **Caregivers do not feel welcomed at schools.**

If school staff are unwelcoming to the caregiver by not inviting them to be involved and engaged in their child's education, caregivers are left feeling that they do not belong in the schools

and that their input in their child's educational process does not matter (Baker et al., 2016; Hill & Taylor, 2004; Koro-Ljungberg et al., 2011). These barriers identified in the literature hinder parental involvement and engagement and may make it difficult for caregivers to develop a partnership with school staff, making their child's navigation toward high school graduation a challenge. Concentrating on the barriers that caregivers have expressed in the literature is a possible way to advance from parent involvement to engagement.

### Benefits to Parental Involvement

One benefit to parent involvement is the possible collaboration or relationships that can be formed between caregivers and school staff. These collaborations through parental involvement and engagement can possibly help avoid potential issues between students and staff. Collaborative relationships between caregivers and school staff establish a foundation that serves both parties well when issues do arise (Carpenter et al., 2016; Prezant & Marshak, 2006). These relationships, built on trust, allow caregivers and school staff to approach each other in a respectful manner when issues may arise (Prezant & Marshak, 2006). These relationships also make it more likely that services will be provided if the parent or child needs additional support.

Besides improved relationships with children and school staff, caregivers spoke of the personal benefits they acquired from parental involvement (Carpenter et al., 2016; Hall & Quinn, 2014). Caregivers realized the importance of their children's education. They also saw the value in pursuing or furthering their own education as well. Making a living for their family was still a priority but caregivers looked at obtaining higher education in the future as a way of gaining financial stability (Carpenter et al., 2016; Hall & Quinn, 2014).

Caregivers affirmed that they gained self-confidence through their participation in school activities (Carpenter et al., 2016). Another valuable tool that caregivers gained through their involvement and engagement was self-efficacy (Blok et al., 2007; Carpenter et al., 2016; Hoover-Dempsey et al., 2005; Hoover-Dempsey & Sandler, 1995). Self-efficacy is defined as the caregivers making decisions to be active in their child's learning process even though they may face adversity to being involved and engaged (Hoover-Dempsey et al., 2005).

### Caregivers Navigating Children with Disabilities

Navigating a child with disabilities comes with challenges. Caregivers of children with disabilities may be cautious in admitting to professionals that their services are not helping for fear their children will be hurt in some way by their disapproval (Prezant & Marshak, 2006). Help that caregivers of children with disabilities received from professionals was not always viewed as helpful and at times was unwanted. Caregivers navigating children with disabilities determined that professionals who assisted in developing their child's self-esteem were the type of individuals they preferred to interact with (Judge, 1997; Prezant & Marshak, 2006).

Besides unwanted assistance at times from professionals (e.g., teachers, school social workers, school psychologists), caregivers navigating children with disabilities may face various challenges or stressors that surfaced in the literature. Depending on the severity of the child's diagnosis, caregivers expressed that they were often stressed with caring for their child with a disability (Kelso, French, & Fernandez, 2005; O'Connell et al., 2013). Financial costs, such as medical care, tutoring, and care giving expenses, were acknowledged by caregivers as stressors (Kelso et al., 2005; Thwala et al., 2015). A common feeling that

caregivers navigating children with disabilities experienced was isolation due to the fact they generally spent a significant amount of time at by themselves caring for their children (O'Connell et al., 2013; Thwala et al., 2015).

Professionals who work with children and their caregivers may want to consider parental input. Without the parental perspective, professionals may implement services to children that parents may view as unhelpful (i.e., not being familiar with or not following the individualized services or accommodations within the child's IEP or 504 Plan); (Prezant & Marshak, 2006). Misunderstandings between caregivers and school staff continue to exist possibly due to the fact school staff do not have personal firsthand knowledge of navigating children with disabilities, so they can not relate to parents (Westling, 1996).

### Caregivers Navigating Children with Invisible Disabilities: How Their Journey Is Different from Caregivers Navigating Children with Physical Disabilities

Navigating children with any type of disability can be stressful. Researchers conclude, however, that caregivers navigating children with hidden disabilities have different experiences regarding securing services and supports for children than caregivers navigating children with physical disabilities (Francis, 2012; Home, 2008). School staff may not want to acknowledge that the child has a disability since it is invisible (Koro-Ljungberg et al., 2011). A caregiver who participated in a study expressed the opinion that some school staff still believe attention deficit disorder and ADHD are not real disabilities since they are invisible (Koro-Ljungberg et al., 2011). It needs to be proven to them that these invisible disabilities are just as real as a physical disability (Francis, 2012; Koro-Ljungberg et al., 2011).

Due to the resistance to providing support and services to children with invisible disabilities, caregivers navigating children with invisible disabilities may take on a more hostile stance when interacting with school staff because they may be overwhelmed (Blum, 2007; Lightfoot, 1981; O'Connell et al., 2013). Blum (2007) utilized the term vigilante instead of advocate when describing caregivers navigating children with disabilities. Blum concluded that the term vigilante was more of a fitting description of these caregivers than advocate. Caregivers raising children with disabilities are often put into combative situations working with professionals (Blum, 2007; O'Connell et al., 2013). Blum (2007) wrote:

Finally, I seized the term vigilante to denote both the intensified monitoring of the child and oneself and the need to take the 'law' into one's own hands when advocating on behalf of one's vulnerable child. (p. 212)

Researchers concluded that if caregivers expressed concern or questioned professionals about their students' progress, particularly during IEP meetings, they were labeled as hostile or uncooperative. Researchers suggest that caregivers secure advocates to speak on their behalf when interacting with school staff (Blum, 2007; Westling, 1996). Professional advocates cautioned caregivers to never attend IEP meetings by themselves and to gain knowledge about the differences between federal and state disability laws (Blum, 2007).

Caregivers navigating children with hidden disabilities often have personal judgments rendered against them when their child does not meet societal expectations (Home, 2008). Caregivers' parenting skills may be called into question rather than professionals' believing that the child has a documented hidden

disability (Francis, 2012; Home, 2008; Kelso et al., 2005). Caregivers (particularly mothers) navigating children with hidden disabilities are sometimes even blamed for their child's behavior and diagnosis (Home, 2008; Francis, 2012). Society has been set up to blame mothers for their children's conditions, but not fathers (Francis, 2012).

As the child with an invisible disability gets older, and if their behavior still does not meet society's expectations, the probability that the caregiver will be criticized for their child's invisible disability is greater. The assumption is that as the child grows up, they should be able to control themselves and meet society's expectations (Francis, 2012). Researchers concluded that professionals need opportunities to study various disabilities and families through field placements and research in order to learn how to support families raising children with all types of disabilities (Home, 2008). Caregivers navigating children with invisible disabilities have a different journey securing services and supports for their children since they are often blamed for their child's disability. Students with invisible disabilities are mainly tolerated instead of seen as unique with something special to offer in the classroom (Maxam & Henderson, 2013). In contrast, a caregiver navigating a child with a physical disability rarely is blamed for their child's condition.

## METHODS

In early 2019, a qualitative case study was conducted in a mid-western city with caregivers whose children attended a traditional high school in an urban school district. The caregiver participants selected to participate in this study were four African American females, (Marie, RoShawn, Latrice, and Jenee), who were raising males with invisible disabilities. Caregivers ranged from the ages of 21 years to 42 years old at the time of the study. All the names of participants have been masked by pseudonyms to protect identities. This was done to ensure that no retaliation would be taken against the caregivers or their children since they lived in the community and attended CHS. The group included biological mothers and an older sister raising her two younger brothers after their mother passed away the year before.

The children all attended the same high school and were either in 11<sup>th</sup> or 12<sup>th</sup> grade during the time of the case study was conducted. The time frame within which children were diagnosed with their invisible disabilities ranged from birth to as recently as two months prior to the study. The children possessed a variety of invisible disabilities: ADHD, sensory disorder, crohn's disease, right cerebral maldevelopment, speech impediment, and diabetes. Quotes from the participants detailed both their personal experiences of raising a child with an invisible disability and their child's experiences with having an invisible disability during their late high school years. The participants also provided insight into their child's experiences through their narratives. The participants' responses are arranged in the order that they were interviewed.

## Research Design

This qualitative research design employed the case study method, a method of design found in several areas of the social sciences. Even though a quantitative study could have been done, the decision to conduct a qualitative study was based on recommendations from scholars such as Creswell (2007, 2014) and Patton (1990). A qualitative study allowed to gather and analyze the data necessary to make suggestions on how caregivers and school staff could more efficiently work together in the best interests of children as they move towards high school

graduation. The investigator can acquire an in-depth examination of activities and events that may have occurred for one or more individuals (Stake, 1995; Starman, 2013; Yin 2009, 2012 as cited in Creswell, 2014). Conducting a study with a small sample size aided in creating an intimate situation that allowed to get to know participants better. Creswell (2007) suggested that four to six participants in a qualitative study is an adequate sample size based on research findings by Stake and Yin: "When a researcher chooses multiple cases, the issue becomes, 'How many cases?' There is not a set number of cases. Typically, however, the researcher chooses no more than four or five cases" (p. 76). The logic for the small number of cases is that a substantial amount of data must be obtained for each case. To conduct a sound qualitative study, the researcher should have familiarity with the investigation topic (Brantlinger et al., 2005; Sutton & Austin, 2015). One of the co-authors' personal experience with navigating a child with an invisible disability through the K-12 educational system to high school graduation assisted during this study. Participants felt more comfortable sharing and allowing the co-author to report their experiences due to the fact she has already been through this process with her own child.

Another reason a qualitative research study was conducted so the stories of marginalized populations could be told (Creswell, 2014; Pugach, 2001). Qualitative studies grant the opportunity for participants' voices to be heard through the research (Hoepfl, 1997). Additionally, the voices of underrepresented populations detailing how they have personally been oppressed are heard more clearly through qualitative research (Brantlinger et al., 2005; Creswell, 2014; Pugach, 2001). Qualitative research provides participants an opportunity to convey their experiences in their own words: "By focusing on participants' personal meanings, qualitative research 'gives voice' to people who have been historically silenced or marginalized" (Brantlinger et al., 2005, p. 199).

## Selection and Sampling Methods

Due to the large size (student population) of the PS district, we decided to focus the study on one traditional high school within the PS district, CHS. The focus on one school shed light on how caregivers and school staff at one school interacted when the child had an invisible disability. The four participants were recruited in the following ways. First, flyers were posted in various businesses that caregivers frequent (e.g., grocery stores, nail salons, fitness clubs, churches) within a 10-mile radius of CHS. Second, snowballing or chain referral sampling, which is a purposeful sampling, method was utilized. Purposeful sampling is defined by Patton as choosing subject matter that individuals can gain knowledge from (1990). Through snowballing, we relied on participants to refer individuals who are a part of their social network and familiar with the topic. Participants recruited in this manner should offer additional information for the researcher to analyze (Mack, Woodsong, Macqueen, Guest, & Namey, 2005; Patton, 1990).

The selection process criteria for caregiver participation in the study called for individuals to be a parent or guardian of a child with an invisible disability. The child had to attend CHS and be in the 11th or 12th grade. Individuals selected to participate in the study were notified and given an opportunity to consent to the study. Informed consent can be secured orally or in a written format. A written consent was acquired from the participants who were selected for the study, and a copy of the form was provided to participants for their records.

### Data Collection Methods

Data was collected through multiple approaches: semi-structured face to face interviews; member checks; and a follow-up interview with two of the study participants as well as document analysis. By comparing the data gathered from a number of sources, the researcher determined if data was accurately interpreted by participants. Utilizing multiple data sources assisted in controlling personal bias to the subject matter, (one of the co-authors raised a child with an invisible disability).

### Semi-Structured Interviews

Once the four participants were selected to participate in the study, individual, in-person, semi-structured interviews were conducted. The duration of the interviews was 45 to 90 minutes. The interviews were audio recorded on a tape recorder. Notes were hand-written during the participant interviews to capture their responses to questions through another method. The questions that were asked to participants during their semi-structured interviews are featured in Appendix A. Notes were later transcribed, coded, and compared them to written notes to develop common themes. After the interviews, audio tapes and notes were secured in a locked cabinet that only the co-author has access to.

### Member Checking

It is a popular technique utilized in qualitative research (Birt, Scott, Cavers, Campbell, & Walter, 2016; Creswell, 2014; Hoepf, 1997). Member checking has various purposes. This practice can be used to verify the accuracy of the information collected. Participants can read their own words to make sure that the researcher has comprehended their thoughts and experiences in an accurate manner (Birt et al., 2016; Harper & Cole, 2012). Two member checks were conducted with participants, who read and determined if their answers were interpreted correctly. Within two weeks, participants were contacted via e-mail. The co-author provided participants with a copy of their interview transcript. They had an opportunity to read and determine if their answers to questions were interpreted correctly from their semi-structured interview. Once the original Findings chapter was written participants were provided a draft of their section. They were able to read the contents in a more polished format. Besides attempting to make sure that the co-author correctly interpreted what each participant expressed previously in their individual interviews, a member check also helped to reduce any personal bias that the co-author may have had as a researcher since they have experience with the subject matter (Birt et al., 2016; Pugach, 2001).

### Follow-up interview

After all the individual in person semi-structure interviews were conducted with all four participants they were invited to a focus group. Since all of the participants were not able to attend the focus group, a follow-up interview was conducted instead. Participant 1, Marie, planned to attend, but the day before her son Nick was admitted to the hospital again for his Crohn's disease. Participant 3, Latrice, was traveling back home from a basketball tournament with her son Justin and was unable to access a WiFi connection. Participant 2, Roshawn, and Participant 4, Jenee, were both present for the follow-up interview. Providing multiple occasions for research participants to be interviewed such as a follow up interview has various benefits: "Subsequent interviews also provide an opportunity to return to participants interviewed early in a study with new information that surfaces in interviews with individuals recruited later in a study" (Olson, 2016, p. 47). The participants were asked open-ended questions to prompt their

views on the subject matter (Creswell, 2014). The questions that were asked of the participants during the follow-up interview are displayed in Appendix B. The co-author served as the facilitator of the follow-up interview session. In addition, the session was audio taped and later transcribed to uncover themes.

### Document analysis

Since the sample size was small, a document analysis was conducted to acquire extra materials from participants. Examining printed or electronic material to obtain supplemental information will enhance the value of the research (Bowen, 2009). There are various reasons why implementing document analysis into qualitative research studies are important. Analyzing more data helped me build a potentially stronger case around the examination of supports and services schools voluntarily provide to parents.

Individualized Education Plans (IEP's) and 504 Plans were requested from caregivers. The intention for requesting the IEP's and 504 Plans was to determine what supports or services parents with children with invisible disabilities are aware of in the PS school district (CHS) and to determine if they are really receiving the services and supports outlined in these legal documents. Different conditions call for the different interventions that may be present either in an IEP or 504 Plan. Individualized Education Plans and 504 Plans from caregivers were asked for during the semi-structured interviews. Participants 1's and 2's children still had IEPs. Participant 2 provided me with correspondence between herself and her son's IEP coordinator. Due to the family moving recently she could not locate the actual IEP document. Participant 3's son's 504 Plan was stopped by the school district at the end of elementary school, and Participant 4's brother had recently been diagnosed with his invisible disability. At the time, he was receiving accommodations for his invisible disability until an official 504 plan could be drawn up.

## RESULTS/FINDINGS

### Marie

Marie was a 40-year-old African American female who is married with four children (one girl and three boys) at the time of the study. Her middle son, "Nick," was the focus of our interview. Nick was classified as a 12<sup>th</sup> grader at CHS. Nick was diagnosed with ADHD and a sensory disorder in the 3<sup>rd</sup> grade. At that time, Nick was enrolled in another school district and an IEP was obtained. Marie and her family moved to and Nick was enrolled at a middle school in the PS district when he was in the 6<sup>th</sup> grade. His IEP transferred over. In 7<sup>th</sup> grade, it was discovered that Nick had Crohn's disease. Crohn's disease is an inflammatory bowel disease that effects the lining of the digestive tract (Mayo Clinic, n.d.). Nick's diagnosis of Crohn's disease and accommodations/supports were added to his IEP.

During her one-on-one semi-structured interview, Marie did not indicate at least one consistent person either at CHS or in the community that helped her navigate the K-12 system and secure accommodations/services for her son. The lack of social relationships or social networks with individuals at CHS and in the community made the difference in her child's not graduating on time. Unfortunately for Marie and her son Nick, the harsh reality of the old saying "It is not what you know, but who you know" turned out to be true (Guantlett, 2011).

One of the co-authors asked Marie if she felt like the lack of attention that her son received was due to race. She was very open in her response and did not feel like the negative treatment they received has been racially motivated:

I don't think it has anything to do with race. I don't think they put in the effort and the caring. And really that is what it is and it's sad. I think they look at it like this we have 1,000 kids; 600 of them want to do good and 400 of them are giving us trouble. Let's get them out of here as fast as we can. We haven't had support by the White staff or the Black staff for that matter. I think they literally do not have the ability to support the children, the way the children deserve to be supported, primarily because a lot of them do not have the desire to be supportive anymore and maybe they don't have the support they need. That's sad isn't it? But it is not racial.

### Roshawn

Roshawn was a 42-year-old African American female at the time of the study. She is married with six children. Roshawn is currently a business owner, but in the past, she worked in the health field as a nurse and in the non-profit sector as an advocate for disabled individuals. "Cairo" is Roshawn's fifth child and her only child with an invisible disability. At the time of the study Cairo was in the 11<sup>th</sup> grade at CHS with an active IEP.

During her semi-structured interview Roshawn stated, "pretty much at birth" her and her husband knew Cairo was going to have challenges. Cairo was diagnosed with right cerebral maldevelopment as an infant: "So that means the right side of the brain is not developed." Roshawn observed Cairo's development was not the same as her other children: "At one-year-old, I noticed differences in him versus my other children. The speech patterns were not there for a one-year-old, and his behavior was very aggressive, particularly at daycare." When he was a baby and toddler going to daycare, Roshawn and the daycare provider collaborated to come up with strategies to support Cairo. In addition, the doctor also gave Roshawn suggestions on the types of food to feed Cairo when he was younger because he was overweight and very tall for his age. When Cairo reached the 6<sup>th</sup> grade, Roshawn decided to secure a formal IEP.

During the one-on-one interview with Participant 2, Roshawn, she spoke of a colleague who helped her secure her son's IEP. Roshawn also sought assistance from a local non-profit agency. An advocate from the organization attended her son's first Individualized Education Plan (IEP) meeting to provide moral support. During the follow-up interview, Roshawn expressed she and Cairo's IEP coordinator, Ms. Stevens, who also served as the head of the special education department, have formed a positive working relationship:

The main teacher that I connect with, her name is Ms. Stevens. She knows me. We actually were all in Target the other day. She ran up to me said Hey how are you? The connection and the rapport is definitely there with her. She knows me very well through Cairo. We have built a rapport too.

### Latrice

Latrice was a 36-year-old African American female at the time of the study. She is a single mother to three children (1 boy and 2 girls). Latrice is a director at a local non-profit agency. Her son, Justin, was 17-year-old and in the 11th grader at CHS when the study was conducted. Justin was diagnosed with a speech impediment when he was 4-years-old while he was attending Head Start. Once Justin graduated from Head Start, they took care of transferring his 504 Plan to the elementary school that he attended. Mr. Benson was the speech pathologist who worked with Justin when he was enrolled in Head Start and during elementary school. After Justin finished elementary school,

Latrice was told by school staff that his 504 Plan was going to be discontinued even though she wanted him to continue receiving the services through the 504 Plan.

Even though Justin's 504 Plan was discontinued, during her semi-structured interview Latrice spoke highly of individuals within the PS district and in the community that helped her and Justin. Latrice sought other avenues to help Justin with his speech impediment when PS determined that Justin was no longer eligible to receive services. The coordinator at a local non-profit agency helped Justin informally with his speech when he was enrolled in the after-school program during middle school. Latrice also put Justin in leadership roles as a peer mentor at a local church and through another non-profit agency, where he was paid to be a peer educator to younger children.

### Jenee

Jenee was a 21-year-old African American female at the time of the study who was raising her two younger brothers who were both students at CHS. Jenee has been raising her brothers for a year since the death of their mother from complications of diabetes the year before the study was conducted. Gavin was a 16-year-old 11th grader at CHS at the time at the time of the study. Gavin was diagnosed with diabetes about two months prior to the study. Since the diagnosis is so recent, when the study was conducted a 504 Plan had not been drafted yet, but Gavin was receiving unofficial accommodations. When asked how it was discovered that Gavin has diabetes, Jenee stated he was not feeling well, and she made him a doctor's appointment: "It really wasn't anything major that happened. He just wasn't feeling good, so I made him an appointment to see a doctor." After Jenee provided documentation to the school that Gavin has diabetes, she and some of the school staff had some conflicts over whether the documentation she provided was good enough proof.

During her semi-structured interview Jenee expressed that she was able to create relationships with two individuals as the school; the school nurse and the other was his past site coordinator. The school nurse intervened when other CHS staff were giving Jenee a hard time about the documentation that she provided to staff to prove that Gavin was diagnosed with diabetes. The school nurse attended one of Gavin's doctor's appointments and wrote everything down that the doctor said. She then drafted a report and sent the information to the school staff who questioned the documentation that Jenee provided and made sure that Gavin's teachers were aware of his newly diagnosed condition. She made it clear Gavin truly had diabetes, and while he was at school, it is their responsibility to provide accommodations to him. The school nurse explained what a 504 Plan was to Jenee and suggested reasonable accommodations that would be good for Gavin until a formal 504 Plan was written up with the school's 504 coordinator.

Besides the school nurse, Jenee also spoke very highly of another school staff person at CHS, Mrs. Young. In the past, Mrs. Young was a site coordinator with a local non-profit organization stationed at CHS. Gavin used to be one of her caseload students. Per Jenee, after Gavin was diagnosed with diabetes, he started skipping school. Mrs. Young noticed Gavin's absences from school. Even though it was no longer in her job description to monitor his academics, attendance, and behavior, Mrs. Young's concern for Gavin did not stop. Mrs. Young contacted Jenee and asked her if she would come to the school for a meeting with Gavin that she would mediate. During the meeting, Gavin expressed that he was scared about his diagnosis. Mrs. Young was able to talk Gavin and Jenee through the situation. Jenee stated that she appreciated Mrs. Young: "She

didn't have to contact me. She talked to us and during our meeting I felt like she was genuine.”

Participants 2-4's children were on track to graduate high school in 2019 and all three young men graduated from CHS in June 2020. Caregivers were able to form relationships with at least one person at CHS or non-profit agency in the community. Their children's needs were met based on this assistance from the individuals in their social network.

## DISCUSSION

### Significance of the Study

Researchers do not often explore the experiences of caregivers when studying children with disabilities even though their voices are important to a child's growth and development. According to Prezant and Marshak (2006), there is a relatively small but slowly growing body of research that addresses experiences of caregivers rearing children with disabilities overall; there is even less research on caregivers rearing children with invisible disabilities. Telling the stories of individuals with disabilities or the people who live with individuals with disabilities is imperative if we are to learn from them: “These personalized accounts provide insight into how classification and treatment are perceived by people with disabilities and their families” (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005, p. 199). In telling stories of these marginalized groups, others may begin to comprehend the needs and the struggles of the individuals who are a part of these oppressed populations. In turn, those who hear these stories may provide to aid those in marginalized populations (Pugach, 2001). Individuals who are not a part of marginalized populations may not be aware that everyone in the world is not situated to receive the same advantages as they are (Barton, Drake, Perez, St. Louis, & George, 2004).

### Themes that surfaced for the one-on-one interviews and follow up interview

The commonality that surfaced between the participants experiences after analyzing the data from the one-on-one interviews and follow up interview were social connections or lack of social networks. All the participants except one were able to name individuals either at CHS or in the community that they have formed social relationships with that are helping them navigate and secure services for their children to guarantee that their child's needs were being met. The children of the three participants who have been able to create social connections with individuals either at CHS or in the community graduated from high school on time.

During the follow-up interview participants were asked a series of questions. Even with the social connections that have been built between participants and certain CHS staff, participants reported discouraging occurrences that have stalled their involvement in their child's education. Roshawn and Jeneé cited feeling unwelcomed when they walk through the doors of CHS, not being invited to the school except for IEP meetings or discipline issues, that they experienced cultural/social insensitivity and dealt with the absence of follow through by some CHS staff. Even with feeling slighted, Roshawn and Jeneé continued to be involved and wanted to be involved beyond the occasional calls in relation to their child's behavior and to schedule IEP meetings.

### Limitations

The findings of this study were limited by various factors. The study was focused on parents navigating children with invisible disabilities. The participants' children were enrolled at CHS,

only one of the four high schools in the PS district. The decision to conduct a study there is mostly based on location convenience to the co-author. Children were either in the 11<sup>th</sup> or 12<sup>th</sup> grade. Late high school is generally when children prepare for high school graduation. In the study, two of the children had IEPs, one child's 504 Plan was stopped by the district, and one child with a diagnosis of an invisible disability was awaiting his 504 Plan. School staff were providing accommodations until an official 504 Plan can be drafted. The findings only pertain to a small sample size of four participants sharing their experiences with navigating their children who have invisible disabilities through high school graduation from a single school. Having a small sample size did not allow for a diverse array of participants to be attained. In addition, conducting a follow-up interview did not provide all participant views to be expressed. All the participants are of the same race (African American) and gender (female). The participants' children are all males. My personal experience (bias) with navigating a child with an invisible disability is also a limitation of this study.

### Collaborative Evaluation Approach

A collaborative evaluation requires a substantial degree of collaboration between evaluators and stakeholders in the evaluation process to the extent that they are willing and capable of being involved (Rodríguez-Campos & Rincones-Gómez, 2013). A collaborative evaluation is able to examine how to assist caregivers raising children with invisible disabilities and aid in their desire to be more present in their child's academic life. This type of approach provides a sound perspective of not only the caregivers needs but also the child and school staff as well. The working relationship between families and school staff should be thought of a triangle. Experiences and viewpoints of parents, children, and school staff are all in this model, but the children should be the focus (Lightfoot, 1981).

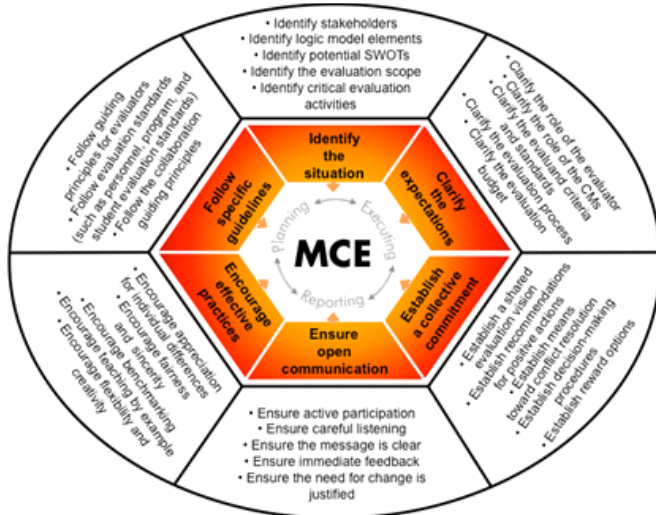
Throughout interactions, caregivers and school staff need to remember that the reason they were brought together is because of the child (Lightfoot, 1981). Having a clear understanding of the situation increases stakeholders' involvement in the collaborative evaluation because they are confident about its expectations. When interacting with each other children may be helped: “When adult figures begin to focus on their reason for coming together in the first place and begin to act in the best interest of the child, some of their defensiveness will fade away and the territorial lines will erode” (Lightfoot, 1981, p. 103). Until caregivers and school staff truly shift their focus to the best interest of the child, the child will not be helped (Lightfoot, 1981; Pena, 2000). If school staff do not believe that invisible disabilities truly exist, then partnerships with caregivers and facilitating student academic success may be difficult.

There are numerous models that can be utilized to gauge parental involvement and engagement among caregivers raising children with hidden disabilities. After further exploration of several collaborative frameworks, it was determined that the Model for Collaborative Evaluations (MCE) could be used to provide stakeholder feedback. The MCE is a framework for guiding collaborative evaluations in a precise, realistic, and useful manner (Rodríguez-Campos & Rincones-Gómez, 2013). The MCE framework is part of a group of stakeholder involvement approaches where the evaluators promote support and cooperation for conducting evaluations (Fetterman et al. 2018).

The MCE can be adapted to address specific needs because the model helps to actively engage the key stakeholders as collaboration members (CMs) throughout the evaluation process. The model revolves around a set of six interactive



components specific to conducting a collaborative evaluation to establish priorities and achieve a supportive evaluation environment (e.g., Rodríguez-Campos, 2015; Rodríguez-Campos & Rincones-Gómez, 2018). The following are the MCE components: (a) identify the situation, (b) clarify the expectations, (c) establish a collective commitment, (d) ensure open communication, (e) encourage effective practices, and (f) follow specific guidelines (see Figure 4).



**Figure 4. The Model for Collaborative Evaluations. Reprinted from Collaborative Evaluations Step-by-Step (p. 14), by L. Rodríguez-Campos & R. Rincones-Gómez (2<sup>nd</sup> ed.), 2013, Stanford, CA: Stanford University Press. Copyright 2013 by Liliana Rodríguez-Campos and Rigoberto Rincones-Gómez. Reprinted with permission.**

Each of the MCE subcomponents, shown as bullet points, includes a set of ten steps suggested to support the proper understanding and use of the model. Consequently, checklists can contribute to the improvement of validity, reliability, and credibility of an evaluation. This model has been introduced in many countries around the world in a wide variety of settings including business, nonprofit, and education. In the last decade, it has grown in popularity along with similar approaches, bringing together evaluators and stakeholders from different disciplines and cultures. The MCE covers the broadest scope of practice, ranging from an evaluator consultation with a client to full-scale collaboration in every phase of an evaluation.

**Purpose of Conducting an Evaluation**

A purpose of the evaluation would be to examine the experiences of caregivers raising children with invisible disabilities. Particularly, how participating in parental involvement and engagement opportunities could assist them in advocating for their child's needs and in developing working relationships with school staff. The quality of the decisions within the collaborative evaluation depends on clearly defining, with key stakeholders, the evaluation in terms of all the possible ways to solve it. Then, findings of the evaluation could provide insight on how caregivers would like to receive information, support, and resources from CHS and PS district staff. In addition, the evaluation would be designed to study what caregivers may feel is lacking in their experiences at CHS and how to remedy the situation.

Based on the collaborative discussions with key stakeholders, the following would be goals of the evaluation: (a) provide caregivers navigating their children with hidden disabilities a voice to better secure services and support on behalf of their children; and (b) provide educators from urban school settings

(more specifically PS/CHS) with ideas about how to partner and assist caregivers navigating their children with invisible disabilities to bring about a smoother path towards high school graduation. The findings applying the MCE could potentially bring forth information caregivers and educators can utilize to refine the ways that they interact and support each other, as children with invisible disabilities move towards completion of secondary education.

The personal experience of one of the co-authors with navigating a child with an invisible disability through the K-12 educational system to high school graduation would assist during this evaluation. Key stakeholders may feel more comfortable sharing and reporting their experiences since one evaluator has already been through the process with her own child. The voices of underrepresented populations detailing how they have personally been oppressed need to be heard more clearly through research (Brantlinger et al., 2005; Creswell, 2014; Pugach, 2001).

Because stakeholders, in this case caregivers, children, and school staff are not communicating with each other, misunderstandings regularly develop, and the child's needs are not met. Misunderstandings between caregivers and school staff continue to exist possibly due to the fact school staff do not have personal firsthand knowledge of interacting with children who have disabilities, so they can not relate to caregivers (Westling, 1996). It is the hope that by conducting an evaluation utilizing the MCE would reduce the barriers of services not being provided to children with invisible disabilities, students not graduating on time and parental involvement and engagement within school buildings being more accepted by school staff.

**CONCLUSION AND RECOMMENDATIONS**

During the 1 study caregivers reflected on situations that they experienced with interacting with PS and CHS staff: not feeling welcomed when going to their child's school building, only being invited to the school for IEP meetings, only being contacted about discipline issues, cultural and social misunderstandings, and not being invited to engage in school events. An evaluation using the MCE as a framework to identify elements could help caregivers, youth, and school staff foster shared appreciation for each other's differences. Key stakeholders may be willing to work collaboratively in the evaluation because they are part of the decision-making process with their opinions valued. The use of the MCE would provide an increased breadth of knowledge within the scope of raising children with invisible disabilities and parental involvement and engagement.

Utilization of the MCE could bring forth valuable information to assist evaluation stakeholders, such as caregivers, children, and school staff. Parent/guardian involvement and engagement is essential to youth with invisible disabilities. For instance, getting the services that they need to graduate high school, and going on to post-secondary education, vocational training and/or employment. Specifically, the MCE may transform interactions with stakeholders into a joint responsibility process between the evaluators and key stakeholders. The MCE may also help to understand and account for the nature of the work and the full range of stakeholders in the collaborative evaluation process. This model could provide an increased shared ownership that also may lead to an increased quality of information for decision-making and receptivity of findings.

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