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Case study of parents' experiences as their children with hidden disabilities navigate the K-12 system to high school completion

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Case Study of Parents' Experiences as Their Children with Hidden Disabilities

Navigate the K-12 System to High School Completion

by

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Abstract

The experiences of parents navigating through the K-12 school system as their children with invisible disabilities move toward graduation from secondary education are multifaceted. This qualitative study examined the experiences parents are having or not having at Kalamazoo Central High School (KCHS), a traditional high school within the Kalamazoo Public School (KPS) district. The research questions revealed the experiences of parents navigating their children with invisible disabilities. Conceptually, this study was guided by the ecologies of parental engagement (EPE) framework. The teachings of Pierre Bourdieu and his perspective on social capital were also utilized. Data was collected through semi-structured interviews, member checking, a follow-up interview, and document analysis to provide thorough descriptions of the parents' experiences. Four participants were selected for the study from flyer advertisements and utilizing the snowball strategy in which individuals referred other participants. Participants were selected for the study based on the following criteria: their children were currently enrolled at KCHS, in the 11th or 12th 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 provided insight on parents' experiences during their children's progression toward high school graduation and how interactions with KPS staff, particularly those stationed at KCHS, influenced these transformations. 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.

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Chapter 1: Introduction

Parents who are rearing children with hidden disabilities may encounter challenges with school staff as parents help their children navigate through the K-12 system. 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). According to the Invisible Disabilities Association's (2017) 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). 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.

Personal Experience

Consider the account of my experience interacting with school staff regarding my daughter:

My daughter Assia was diagnosed with ADHD when she was in the first grade. I tried to build a partnership with her teacher. I told her to call me anytime there was an issue with Assia. That was a mistake. Her teacher would call and tell me that Assia got a time out for one thing or another at least 3-4 times a week. After school I would ask Assia what happened. She would say, "Mommy, I don't know. She just put me in time out." During that school year I was enrolled in graduate school working towards my

master's degree. At that time, I also worked for a local non-profit agency as a community educator. I would go to all the school districts in Kalamazoo County and teach a curriculum to students at the K-12 level and to college students on various topics. I always dropped Assia off at school. But at least two days a week I would walk Assia into her classroom and get her settled for the day.

During the spring parent/teacher conferences in March 2008 when I walked into the classroom, the teacher and the school principal were present. I thought it was strange that the principal was a part of the parent/teacher conference. As the conversation progressed, the teacher let me know that she was recommending that Assia be held back in the first grade. I countered the teacher's comments with, "You see me face-to-face two days a week. If you felt like Assia was not progressing academically, why didn't you say anything before now?" The teacher replied, "It has taken me all this time to get to know Assia, to make my recommendation." We scheduled another meeting to continue to discuss the possibility of Assia being held back.

During a regular visit to the pediatrician I expressed to him how upset I was following the parent-teacher conference. He let me know that ADHD is a type of invisible disability and the school had a legal obligation to provide reasonable accommodations through a 504 Plan. He gave me suggestions of reasonable accommodations that could be implemented on her behalf. Before the appointment was over the doctor let me know that if the school staff gave me a hard time with getting a 504 Plan to contact him. He was personally willing to assist me with obtaining one.

Besides the information that the doctor provided me, I decided that it also would be helpful to educate myself on ADHD and 504 Plans. I did some research and

discovered a nonprofit agency in my area called ASK Family Services, (formerly known as Advocacy for Kids). The ASK advocate I spoke to requested my home address so she could send me information about Special Education Laws and 504 Plans in the mail. She also offered to attend the next school meeting with me.

On the day of the meeting, I had the ASK advocate in tow, and we were ushered into a conference room where the teacher, principal, and school psychologist were already seated. By the looks on their faces, I do not think they expected me to have an advocate with me. During the meeting I spoke knowledgeably about Assia's invisible disability and shared some of the doctor's suggestions, which were techniques on how to check for her understanding of the directions, redirecting her without causing embarrassment, and preferential seating. The ASK Advocate reinforced that they were required to provide accommodations since Assia had been diagnosed with ADHD. By the end of the meeting, the school staff changed their recommendation from holding Assia back to letting her move on to the second grade if she attended summer school. In addition, they also agreed to implement the accommodations that I presented to them. Phone calls about Assia's behavior immediately stopped.

I often wonder what would have happened if I had listened to the "professionals" when Assia was in the first grade and had allowed her to be held back. My daughter's first grade teacher could have done more to try to teach her after it was confirmed that Assia had ADHD. The teacher exercised power over my daughter (Delpit, 1988), imposing discipline rather than trying to reach her in a more productive way. Assia is an artistic, creative, visual learner, not someone who learns best via lecture. The first-grade teacher's refusal to differentiate her teaching style to accommodate Assia's learning style demonstrated her belief that she was not

responsible for Assia's learning. "Differentiation" is a teaching philosophy that considers how students learn. Essentially, the educator realizes that although students may be the same age, they may differ greatly in their readiness to learn, their style of learning, their experiences, and their life circumstances (Tomlinson, 2000). After the first grade, the majority of Assia's teachers were willing to teach to her strengths and not her weaknesses.

One might assume that since my daughters' first grade teacher and I were of a different race that her actions/reluctance to teach Assia was racially motivated. Based on an interaction that I had with two White mothers whose children were classmates of Assia's in the first grade, I do not feel like our treatment was racially motivated. On the first day of summer school, as we waited for the school bus to pick up our children, both mothers expressed frustration with the treatment of the same White teacher towards them and their White sons. They both felt broadsided at the March 2008 parent/teacher conferences as well. They also did not expect the principal to be present at their parent/teacher conference. In addition, the first-grade teacher recommended that their child be held back in the first grade as well. One mother was a single parent, and the other was married. Since these White mothers had nearly the same experience with their sons with the same White teacher, I concluded that my daughter's and my experience was not racially motived. In my opinion, this was a teacher who was near retirement and who did not possess the willingness to teach children who learned differently and refused to build a partnership with me even though the olive branch was extended by my stating that I would be available for phone calls if an issue arose. She used the phone calls to express everything that she felt was wrong about my daughter, but never what Assia could do or any future potential that she could see in her with the accommodations that were recommended by the pediatrician.

Several questions come to mind for parents who do not share my penchant to persist even when the teacher does not want to partner with them and find other avenues to make sure that the child's needs are met. What happens to parents who do not have flexible work schedules and cannot take time off work to go to their child's school when they get phone calls? What happens to parents who are not educated on legal mandates that protect their child with disabilities, particularly invisible disabilities? What happens to parents that do not know how to research and find agencies and secure an advocate to speak on their behalf? My inspiration for conducting this research was based on my own experiences. The rationale for this study was rooted in my concern for families who lack the agency to get their children's needs met. This study was necessary to answer the questions posed above. Ideally, by enlightening parents that they can play an instrumental role in their children's education, they may achieve the confidence to articulate their children's needs to school staff. Hopefully, these engagements will help foster partnerships between parents and school staff as children with hidden disabilities navigate toward high school completion.

Problem Statement

The experiences of parents who are navigating their children with invisible disabilities through the K-12 school system can be complex. There are major disconnects or misunderstandings between parents and school district staff (Koro-Ljungberg et al., 2011; Lindsay & Dockrell, 2004; Rehm & Rohr, 2002). Parents often complain that they are not aware of the rights that their children have regarding their disability. A study conducted by Rehm and Rohr (2002) concluded that it took a substantial amount of time, years even, for some parents to understand their legal rights regarding educational services for their children. Research has shown parents proclaimed they needed to maintain a careful watch of their children's academic

process throughout the year to ensure that their needs were being met at school (Carpenter, Young, Bowers, & Sanders, 2016; Rehm & Rohr, 2002). For example, school district staff do not always readily give information to parents that, if their child is diagnosed with a hidden disability, he or she may be eligible for a 504 Plan or an Individualized Education Plan (IEP). A 504 Plan focuses on reasonable accommodations for a child while an IEP provides individualized goals for a child who receives special education services. Both 504 Plans and an IEPs are legal documents. Administrators of school districts that already have limited resources and staff may feel as though they are not prepared to meet the obligations of executing a 504 Plan or an IEP in its entirety. Parents were upset about the lack of knowledge and hesitation of school staff in accommodating their children's needs at school. They also expressed that school staff did not inform them of their children's rights and they had to fight for services for their children (Freedman & Boyer, 2000; Lindsay & Dockrell, 2004; O'Connell, O'Halloran & Doody, 2013). Parents felt there was not a systematic way of obtaining the support that they needed regarding their child's education (Epstein, 1985; Freedman & Boyer, 2000). The obstacles described above make it difficult for parents to obtain information, supports, and services for their children with invisible disabilities in order to guide them to high school graduation. A further discussion of legal mandates to protect individuals with disabilities will be provided in Chapter 2, the literature review.

Purpose of Study

The purpose of the study was to examine the experiences parents are having or not having at Kalamazoo Central High School (KCHS), a high school within the Kalamazoo Public School, (KPS) district as they navigate their children with hidden disabilities through the K-12 system to high school graduation. This case study sought to discover the experiences and

supports/services that are and are not available to parents in the KPS district, especially at

KCHS. The hope was that the findings of this case study will provide insight on how parents

would like to receive information, supports, and resources from KPS district staff. In addition,

this study was designed to reveal what parents felt is lacking in their experiences at KCHS. The

major research question that the study sought to answer is as follows: What do parents say their

experiences are in the Kalamazoo Public School district, particularly at Kalamazoo Central High

School when navigating their children with hidden disabilities through the K-12 system to high

school completion? The following aims were goals of the study: (a) to bring to light the

obstacles that parents' experienced while their children with hidden disabilities move towards

graduation from high school; (b) to see how parental 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 parents navigating their children with hidden disabilities a voice to better secure the

needs of parents on behalf of their children; and (d) provide educators from urban school settings

(more specifically KPS/KCHS) with ideas about how to partner and assist parents navigating

their children with invisible disabilities to bring about a smoother path towards high school

graduation.

Conducting a case study centered in Kalamazoo, Michigan, specifically at a high school

within the KPS district, was unique due to the Kalamazoo Promise. The Kalamazoo Promise

endowment was created in 2005. Funded by anonymous donors, The Kalamazoo Promise was

designed as an "economic tool" for the city of Kalamazoo (Miller-Adams, 2009). Depending on

their years of attendance, children who graduate from KPS are eligible to receive 100% of their

tuition and fees paid if they decide to attend a public or private post-secondary institution in the

state of Michigan (The Kalamazoo Promise, 2018). The KPS district is plagued by low rates of high school completion. According to an article published in the school district's online newsletter, the *Excelsior-Live*, in 2017 KPS's graduation rate was 72.9% compared to the state's average of 80.2% (Mah, 2018). These low rates contributed to the high poverty rates present in the community. Without completing high school, it may be difficult for individuals to obtain employment that will help get them out of poverty.

The benefits of possessing a high school diploma are evidenced in the literature (Amos, 2008; Boylan, 1993; Drake et al., 2010). Individuals who have high school diplomas generally earn more income than individuals who are high school dropouts (Amos, 2008; Drake et al., 2010; Jarrett, 2008). In 2007, the average yearly income of a high school dropout was $18,734 whereas for a high school graduate it was $27, 915 (Drake et al., 2010). If the high school graduate obtains a bachelor's degree, they can increase that to an average income of $52,671 annually (Amos, 2008). Besides higher wages, individuals with more education, even a high school diploma, have access to jobs with better health benefits and have better overall life expectancy than individuals who do not have a high school diploma (Amos, 2008; Jarrett, 2008; Drake et al., 2010). Commonly, individuals who are high school graduates live six to nine years longer than high school dropouts (Amos, 2008).

Children with invisible disabilities deserve access and an opportunity to the best life that they can possibly lead. Obtaining a high school diploma is a step to allowing children with invisible disabilities to obtain the benefits of more education.   With proper support, services, and encouragement, parents navigating their children with invisible disabilities can be valuable players in their children's attainment of a high school diploma.

Definition of Terms

This study employed terms that may not be well known to individuals outside of K-12 and higher education settings. The following terms were used in this study:

504 Plan. Covered under Section 504 of the Rehabilitation Act of 1973 PL 93-112, a 504 Plan is a legal document that provides reasonable accommodations to students with disabilities that attend public institutions receiving federal funds (U.S. Department of Education, 1973; U.S. Department of Justice, 2009).

Cultural capital. Also known as educational advancement and expertise, this form of capital allows individuals to achieve a certain level of status in their social circles (Bourdieu, 1986).

Individualized Education Plan (IEP). An Individualized Education Plan, or IEP, is covered under the Individuals with Disabilities Education Act (IDEA). An IEP is a legal document that provides individualized services to students in an educational setting (U.S. Department of Education, 2004; U.S. Department of Justice, 2009).

Individuals with Disabilities Education Act (IDEA). Formally known as P.L. 94-142, the act requires public schools to provide all eligible children with disabilities a free public education. IDEA also requires schools to create an Individualized Education Plan (IEP) for children diagnosed with a disability. Special Education and services detailed in the IEP are specifically defined for each child (U.S. Department of Education, 2004; U.S. Department of Justice, 2009).

Invisible Disabilities. This type of disability can be described as a "physical, mental, or neurological condition that limits a person's movements, senses, or activities that is invisible to

an onlooker" (Invisible Disabilities Association, 2017, "What Is an Invisible Disability?" para.1). In this paper, "invisible" and "hidden" are used interchangeably.

Kalamazoo Promise. Created in 2005, this scholarship program is funded by anonymous donors. Depending on length of enrollment, students graduating from the Kalamazoo Public School district can have up to 100% of tuition and fees covered if they decide to attend public or private post-secondary institutions in the state of Michigan (Miller-Adams, 2009).

Marginalized populations. Occurrences that prevent something or someone from fully participating in the social, economic, and political life, which benefits others in society (Alakhunova, Diallo, Martin del Campo, & Tallarico, 2015).

Parent. A parent is an individual who cares for a child. In this paper, the words "parent" and "parents" are used to indicate anyone who is responsible for the child in question, including grandparents, extended kin, or foster parents.

Section 504 of the Rehabilitation Act of 1973 PL 93-112. This federal civil rights law prohibits discrimination against individuals with disabilities in any program receiving federal funding (U.S. Department of Education, 1973; U.S. Department of Justice, 2009).

Social capital. These are resources associated with being a part of an organization or having relationships with individuals that ensure their needs are being met (Bourdieu, 1986).

Successful transition. This is a process that is the result of comprehensive team planning that is driven by the dreams, desires, and abilities of an individual. A successful transition plan provides the basic structure for preparing a person to live, work, and play in the community, as fully and independently as possible (U.S. Department of Education, Office of Special Education and Rehabilitative Services, 2017).

Urban area. Urban areas have a population density of a least 1,000 people per square mile and a minimum total population of 50,000 people. (Hall, Kaufman, & Ricketts, 2006). The city of Kalamazoo has 74,262 residents (U.S. Census Bureau, 2010). Based on the definition of urban, Kalamazoo, MI, is an urban area.

Significance of the Study

Researchers do not often explore the experiences of parents 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 parents who are rearing children with disabilities overall; there is even less research on parents 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).

I wanted to present the experiences of parents navigating children with invisible disabilities. It was my desire to aid these parents in voicing how participating in parental involvement/engagement opportunities could assist them in advocating for their child's needs and in developing working relationships with school staff. The findings of the study can

potentially bring forth information parents 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.

Conceptual Framework

This case study utilized the ecologies of parental engagement (EPE) framework to analyze the interaction between parents 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). The authors dispute 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 position themselves 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, the authors of the framework wanted 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. I utilized the EPE framework as a lens for my study because I was interested in learning more about the involvement/engagement experiences of parents as their children with invisible disabilities navigate the K-12 school system. This framework helped me because it considered parent experiences and their interactions with educators in urban schools.

Chapter Summary

In this chapter, I shared my personal connection to the study. The research site was

Kalamazoo, MI. Participants had children attending KCHS, a high school within the KPS

district, and have been diagnosed with an invisible disability. I chose these sites for the

following reasons: I live in this area, so accessibility to the site was convenient. When my

daughter was diagnosed with her invisible disability, she was attending a school within the

district and has since graduated from the KPS district. I was interested in learning if my

experiences with KPS staff members is similar or different from other parents' experiences

navigating children with invisible disabilities to high school graduation. Researchers having

personal connections to their subject matter is essential to qualitative research (Brantlinger et al.,

2005; Sutton & Austin, 2015).

In the literature, it is suggested that there are several life-enhancing benefits for

individuals who possess at least a high school diploma (Amos, 2008; Boylan, 1993; Drake et al.,

2010; Jarrett, 2008). Parent, child, and school staff relationships may be important factors in a

child's ability with invisible disabilities to graduate high school. Now that the Kalamazoo

Promise has been established, (a scholarship program available to KPS graduates depending on

their years of attendance within the KPS district), not just children with invisible disabilities, but

a significant number of students may be able to attend college at a free or reduced cost if they

graduate from the KPS district. Children will not be able to use the Kalamazoo Promise if they

do not graduate high school.

Other factors such as the forms of capital a parent has access to, and teacher beliefs may

play a part in a child's not having the necessary support to complete secondary education. It was

my desire that this study provide parents with strategies to communicate their children's needs to

school staff along with a list of the supports and services they believe their children with

invisible disabilities should obtain. Ideally, interactions between parents and staff will lead to

collaborative relationships between these parties. School staff may ease their resistance to

complying with providing the legal support and services that all children with invisible

disabilities should receive. Parents with children with invisible disabilities should not have to

seek additional aid to ensure their child attains assistance that school staff should legally be

providing. But if information is not voluntarily provided by school district staff, parents need to

be prepared to come up with alternatives methods to get their child's needs met.

      Parents need to be aware of the legal mandates that were enacted to protect individuals

with disabilities, including 504 Plans, IEPs, and the fundamentals of special education laws in

addition to the terms associated with these laws. The more knowledgeable parents are about the

legal aspects of these terms, the more likely it is that they can ensure that their child receives

appropriate services and accommodations through 504 Plans and IEPs. Being familiar with these

terms may also help prepare parents who are navigating their children with hidden disabilities

from the K-12 educational system to high school graduation.

Chapter 2: Review of Literature

This literature review examined how parental involvement and engagement can affect parents' experiences during their children's navigation through the K-12 educational system potentially to high school graduation. This chapter is organized based on themes that surfaced in the literature which highlight the importance of parental experiences as they relate to their involvement and engagement in their children's K-12 education. Subheadings provide additional information on the themes in relation to parental involvement and engagement.

Investigating parental 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 parents' experiences as their children with hidden disabilities navigate through the K-12 system to graduation. My intention was to conduct a study to begin to close some of the gaps in the literature. Through this study, I also hoped to help school staff take into consideration parental experiences and reinforce to them the significance of collaborative relationships between them and the parents that support children with hidden disabilities progress toward high school graduation (O'Connell et al., 2013). The overarching research question for this study was as follows: What did parents say are their experiences with involvement/engagement in schools when navigating their children with hidden disabilities through the K-12 educational system, particularly during the 11th and 12th grades? More research in this area may position parents to be valuable players in their child's education and help parents 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. A discussion on relationship development between parents and school staff is necessary to explore, within the context of parental involvement/engagement,

how current relationships between parents and school staff are functioning. 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.

Legal Mandates to Protect Individuals with Disabilities

To understand the legal protections that are available for parents to support their children

with disabilities, it is necessary to provide a brief historical overview of the legal mandates that

are currently in place, particularly in educational settings. The passage of Section 504 of the

1973 Rehabilitation Act had several functions. It banned discrimination based on disabilities for

those who received federal funds, individuals with disabilities were placed into categories based

on their diagnosis, and it ensured reasonable academic modifications (e.g., accommodations) to

students with disabilities (Gil, 2007). This law was also passed to safeguard the civil rights of

individuals with disabilities and guarantee their access to higher education opportunities (Bolt,

Decker, Lloyd, & Morlock, 2011).

The Education for All Handicapped Children Act was passed in 1975 and was renamed

the Individuals with Disabilities Education Act (IDEA) in 1990. This act requires free public

and appropriate education for all children with disabilities (Wolanin & Steele, 2004). The act

was revised in 2004. The revision specifies that local school districts must evaluate students

with possible disabilities and provide them with an IEP (Newman & Madaus, 2015).

The Americans with Disabilities Act (ADA), which also passed in 1990, defines what

reasonable accommodations are for individuals with disabilities. Some examples of reasonable

accommodations include extra time for test completion, preferential seating, and alternative test

sites that can be provided to students enrolled in classes (Garrison-Wade & Lehmann, 2009).

Children diagnosed with disabilities may also have IEPs or 504 Plans.

Many parents may not be aware of the differences between IEPs and 504 Plans. An IEP is utilized for children who receive special education services. For a child to receive special education services, a parent must produce documentation that their child has a disability, (e.g., learning disability, developmental delay, speech impairment, or display behaviors that cause disruptions). Special education services allow for individuals to learn in an individualized manner (e.g., working with a professional one-on-one, working with other students in a small group). A child with a 504 Plan is not eligible for special education services. A 504 Plan incorporates classroom accommodations (e.g., preferential seating, extended time on tests, verbal and visual aids). An IEP should contain measurable goals to guarantee a child's progress. A 504 Plan does not contain goals. An IEP is supposed to be reviewed more frequently, normally every three months, and is adjusted if necessary. A 504 Plan is generally reviewed annually (Wolok, 2013). In addition, children with invisible disabilities are primarily enrolled in general education classes in secondary schools. Sixty-six percent of children with invisible disabilities spend 80% or more of their school day in general education classrooms, up from 47% 10 years ago (Cortiella & Horowitz, 2014). It would be helpful for school staff to review their students' 504 Plans and IEPs to know what disabilities the students have been diagnosed with to be able to provide the student with support. All too often accommodations are not provided to students and the IEP goals are crafted just to keep the school district in compliance with the laws, not to help the children learn (Koro-Ljungberg et al., 2011). Not all children who have been diagnosed with an invisible disability have a 504 Plan or an IEP. If as child has been diagnosed with an invisible disability and there is not a 504 Plan or IEP in place, there are things that school staff can do in order to support the child. If parents supply documentation that the child has an invisible

disability, school staff can implement unofficial accommodations until legal documentation is secured.

Along with legal protections for individuals with disabilities, the federal government also passed a law that discusses parental involvement in schools. In 2001, the No Child Left Behind Act (NCLB) was passed. This law amended the Elementary and Secondary Education Act of 1965. The purpose of NCLB was to close the gap of academic achievement between low-income children and their well-to-do counterparts. The law also spoke to parental participation within school districts (National Council of La Raza, 2007). There are specific sections of the law which highlight the various ways that parents are to be involved in their child's academic life. This is not a complete list, but school districts are expected to create a written strategy to engage parents and families and present projects to parents that they can participate in. Schools receiving Title I funding (schools where 40% of their families are considered low income) have additional obligations to ensure parent involvement and engagement. They are expected to host yearly events to go over programs and hold them at varying times to maximize parental attendance, supply information pertaining to state standards, and offer information on how to enhance children's academic achievement (No Child Left Behind Act, 2001). Even though the law spells out that parents are supposed to be involved in their child's academic life even if they have disabilities, collaborations between parents/guardians and school staff do not always occur in all school districts.

Conceptual Framework

This study utilized the ecologies of parental engagement (EPE) conceptual framework developed by Barton et al. (2004). There is a difference between parent involvement and parent engagement. Parent involvement entails activities or events that school staff develop for parents

to participate in. In contrast, parent engagement is school staff consulting with parents regarding the activities they would like to participate in with their children (Barton et al., 2004; Ferlazzo, 2011). There are various messages that school staff send to parents when they are hesitant to engage parents in school settings.

One message sent to parents is that 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 parents was that their presence at schools is not wanted. Parents 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. Parent 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 parents into classroom spaces due to their own insecurities regarding how to involve and engage parents (Pena, 2000). If parents 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 parents has parents 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 parents. The system is currently set up for schools to have the power and for parents 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 parents. The lack of school staff willingness to partner with parents hinders parents from obtaining services and support for their children (Blok et al., 2007; Lightfoot, 1981; Reynolds & Belvin, 2009).

An additional important component of the EPE framework is that it was constructed under the cultural-historical activity theory (Barton et al., 2004). Integrating culture into the framework allows for involvement and engagement by parents from marginalized populations to be analyzed further. 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 parent who is

navigating a child with invisible disabilities to stay informed about his or her child's educational progress.

Marginalized parents must continue to empower their children and themselves to ensure that their children's needs are being met. Parents should also work towards 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 parents 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. Is it possible that parental involvement and engagement can help solve these two issues? A discussion of parental involvement and engagement is necessary but first a look at why parental experiences are important to their child's education will be addressed.

Parents: Why Are Their Experiences Important in Their Child's Education?

Whether a child has a disability or not, it is hard to conceive that parents are not viewed as stakeholders in the child's education (Lindsay & Dockrell, 2004; Thwala, Ntinda, & Hlanze, 2015). Parents' experiences are critical and should be taken into consideration (Westling, 1996). Marginalized parents 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). Parents 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 parents have a hard time fitting into their child's educational process, a power struggle can ensue between the parent 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 parents 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 parents 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).

Parents: Involvement and Engagement

There are many models available for those who want to involve and engage parents in school settings. Sandra Murray Nettles' (1991) created an extensive template of involvement in school settings. Her model was specifically targeted for individuals working with disadvantaged children. Nettles' model contains four types of involvement: mobilization, allocation, conversion, and instruction. Even though Nettles' model offers a thorough review of involvement, her work is commonly not utilized when analyzing marginalized populations in school settings.

The most well-known and utilized parental involvement model was developed by Joyce Epstein (2009). Epstein's model focused on six types of parental involvement: (a) parenting, (b) communicating, (c) volunteering, (d) learning at home, (e) decision-making, and (f) collaborating with the community. According to Epstein, there are numerous purposes for developing partnerships with school, families, and communities. These partnerships can potentially allow parents the opportunity to develop skills that can aid their child's academic success and create an environment for parents, school, and community to foster collaborations.

Even though this model is utilized widely, school staff in urban districts often fail to use this approach when interacting with both children who have invisible disabilities and their parents.

Many scholars like Larry Ferlazzo are influenced by Epstein's work on parent involvement and engagement. In his 2011 article, Ferlazzo provided an educator's perspective on parent involvement and engagement. He defined involvement as an act of *doing to* while family engagement is *doing with.* According to Ferlazzo (2011), family involvement is the act of school professionals' providing activities for families to participate in with no regard for the interests or desires of parents. Parents are not truly partners in family involvement unless they determine the activities that they would like to engage in concerning their child's education. Ferlazzo challenged school staff not to settle for family involvement and to create an atmosphere of engagement: "The goal of family engagement is not to serve the clients but to gain partners" (Ferlazzo, 2011, p. 10).

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, parents 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 parents 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 parents and teachers to interact with each other formally and informally decline (Carpenter et al., 2016; Hill & Taylor, 2004). Parents 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

Parents 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 parents 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 parents 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 parents who

have children at the secondary level feel as though communication between them and school is

still necessary. Parents concluded they were often frustrated with the exchanges that took place

between them and school staff (Carpenter et al., 2016). Some of parents' frustration came from

not receiving communications in a timely manner regarding events and activities that are scheduled

at the school (Baker et al., 2016). Parents 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 parents 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 parents are already trained to utilize technology (Bardroff-Zieger & Tan, 2012). Parents 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).

Parent work schedules. Parents who work second or third shift have fewer options for involvement in student activities. Parents 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). Parents 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 parent's involvement in school activities (Hall & Quinn, 2014; Hoover-Dempsey & Sandler, 1995).

Parents' childhood experiences. Another barrier that surfaced in the literature was parents' past school experiences from their childhood. School staff may assume if a parent/guardian does not participate in school activities that they are uninterested in their child's education. Memories of mistreatment and trauma that the parent 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).

Parents do not feel welcomed at schools. If school staff are unwelcoming to the parent by not inviting them to be involved and engaged in their child's education, parents 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 parents to develop a partnership with school staff, making their child's navigation toward high school graduation a challenge. Concentrating on the barriers that parents have expressed in the literature is a possible way to advance from parent involvement to engagement.

Alternatives to Traditional Parental Involvement and Engagement

Parents discussed activities in which they took part outside of the school that they considered parental involvement: verbal encouragement, attending community events, and volunteering at local agencies. Participating in these activities provided opportunities to help their children do well in school and allowed the family to spend time together (Hall & Quinn, 2014). Other activities in their child's life can maintain their parental involvement. Parents felt their participation in both school events and non-school events, such as church, YMCA, Boys and Girls Club, library and attending their child's extracurricular activities, showed their commitment to the importance of education (Baker et al., 2016; Carpenter et al., 2016).

Benefits to Parental Involvement

One benefit to parent involvement is the possible collaboration or relationships that can be formed between parents and school staff. These collaborations through parental involvement and engagement can possibly help avoid potential issues between students and staff. Collaborative relationships between parents 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 parents 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, parents spoke of the personal benefits they acquired from parental involvement (Carpenter et al., 2016; Hall & Quinn, 2014). Parents 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 parents looked at obtaining higher education in the future as a way of gaining financial stability (Carpenter et al., 2016; Hall & Quinn, 2014).

Parents affirmed that they gained self-confidence through their participation in school activities (Carpenter et al., 2016). Another valuable tool that parents 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 parent 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). The information presented above furthers the conversation about the barriers of parental involvement and engagement and how parents can personally obtain benefits through their involvement.

Parents Navigating Children with Disabilities

Navigating a child with disabilities comes with challenges. Parents 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 parents of children with disabilities received from professionals was not always viewed as helpful and at times was unwanted. Parents 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), parents navigating children with disabilities may face various challenges or stressors that surfaced in the literature. Depending on the severity of the child's diagnosis, parents 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 parents as stressors (Kelso et al., 2005; Thwala et al., 2015). A common feeling that parents 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 parents 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 parents 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).

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

Navigating children with any type of disability can be stressful. Researchers conclude, however, that parents navigating children with hidden disabilities have different experiences

regarding securing services and supports for children than parents 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 parent 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, parents 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 parents navigating children with disabilities. Blum concluded that the

term vigilante was more of a fitting description of these parents than advocate. Parents 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 parents expressed concern or questioned professionals

about their students' progress, particularly during IEP meetings, they were labeled as hostile or

uncooperative parents. Researchers suggest that parents secure advocates to speak on their

behalf when interacting with school staff (Blum, 2007; Westling, 1996). Professional advocates

cautioned parents to never attend IEP meetings by themselves and to gain knowledge about the

differences between federal and state disability laws (Blum, 2007).

Parents navigating children with hidden disabilities often have personal judgments

rendered against them when their child does not meet societal expectations (Home, 2008).

Parents' 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).

Parents (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) wrote:

> It is likely that mothers are more sensitized to the prospect of blame because they are held
>
> disproportionately culpable for children's conduct and well-being. Mother blame reached
>
> its heyday in the 1940s and 1950s and in the decades that followed mothers become the
>
> scapegoats for everything from schizophrenia to serial killing. (p. 934)

As the child with an invisible disability gets older, and if their behavior still does not meet

society's expectations, the probability that the parent 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 though field

placements and research in order to learn how to support families raising children with all types

of disabilities (Home, 2008). Parents 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 parent navigating a child with a physical disability rarely is blamed for their child's

condition.

What Do Schools Do to Help Students with Invisible Disabilities Navigate?

Through the research for this section, I was unable to uncover any specific strategies that

schools universally utilize to help students with invisible disabilities navigate through the K-12

educational system and move on to high school graduation. I did uncover suggestions within the

literature that schools could use to assist students with invisible disabilities navigate to high

school graduation. An initial step schools can take is to read and attempt to comply with the

accommodations and instructions laid out in these students' 504 Plans and IEPs. If there are

conditions that the school staff are not familiar with, they may want to think about being open

minded before passing judgment. A medical professional diagnosed the child with an invisible

disability. School staff probably do not have the training to contest the disability diagnosis even

though its existence is invisible. A suggestion for school staff is to research invisible disabilities

to get further clarification (Koro-Ljungberg et al., 2011). In addition, using the parent as a

resource could also be helpful. Reaching out to the parent would begin to form a bond between

the parties. It may be a very difficult situation to work with students and their parents if you

unfamiliar with the condition.

Listening to children with an invisible disability is important 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 child's should be the

focus (Lightfoot, 1981). Throughout interactions, parents and school staff need to remember that

the reason that they were brought together is because of the child (Lightfoot, 1981). If adults

remove their egos 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 parents 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 parents and facilitating student success may be next to impossible.

How Do Schools Help Parents or Not Help Parents with the Navigation Process?

As mentioned above, there is no clear-cut system of how schools help students and no established strategy that schools use to assist the parents of children with invisible disabilities in helping their children navigate from the K-12 system to high school graduation. Schools could feasibly implement the following strategies to involve parents navigating children with invisible disabilities. Please note that some of the strategies that will be discussed were mentioned earlier in this literature review.

Moving from involvement to engagement is a way that school staff can include parents in their child's educational journey and help parents. Researchers concluded that school staff can start this process by providing parents with information about activities that they can do at the school and outside the school building to help their child flourish (Baker et al., 2016). Providing suggestions of activities that parents could do with their children at home could reassure parents that they can still be involved and engaged in their child's life even if they are not able to attend school events. Activities such as sporting events, taking the child to the library, and any other activities can still spark a child's learning process (Baker et al., 2016). Before school staff come up with activities for parents to participate in, it would be helpful for school staff to survey

parents first to figure out the best days and times, and the types of activities the parent would like to participate in.

Another strategy is to move from involvement to engagement as described by Ferlazzo (2011). The school district that he worked for in California conducted summer home visits. He discussed how he and his colleagues performed visits to the homes of their students before the school year started. Ferlazzo concluded the visits developed relationships between school staff and families because school staff were able to focus on listening to the family's needs and wants in the comfortable environment of their home. Ferlazzo (2011) wrote:

> Our primary goal is to listen to the wisdom that parents have gained in more than 14 years of raising their children. We want to learn about their hopes and dreams for their children and discuss how the school can work with them to make those dreams a reality.
>
> (p. 13)

School staff can be instrumental in the process of moving from parental involvement to engagement.

Chapter Summary

In this chapter several concepts were explored. Information on legal mandates that are in place to protect individuals with disabilities and encourage parental involvement and engagement was supplied. Parental experiences are important because they are stakeholders in their child's education. The experiences of parents navigating their children with hidden disabilities within the KPS system to high school graduation is the focus of this study. How parents are involved or not involved in their child's education was also highlighted in this chapter. Parental involvement and engagement prepare the parent to be better equipped with knowledge regarding their child's academics, behavior, and school activities. Alternative

parental involvement and engagement activities also provide opportunities for parents and school staff to build relationships with each other. Even though the activities and events do not occur on school grounds, they still may be influential to the child and the parents.

When parents are not involved in their children's school life barriers may occur. Barriers to parental involvement and engagement were cited as parent work schedules, technology, communication, and parent's past childhood experiences with education. These barriers may create an environment where parents are oblivious to their child's progress. Relationships can also be strained between parents and school staff and hinder parents from being players in their child's educational process.

Parents who are welcomed and invited to participate in their child's education obtain personal benefits. The desire to further their own education, become financially stable, and to spend more time with their child were showcased as personal parental benefits to involvement and engagement. Another benefit to parent involvement and engagement is self-efficacy, the act of choosing to be involved in their child's education even when faced with hardships.

Parents navigating children with disabilities may encounter various stressors from time to time. Financial issues and feelings of isolation were named as common stressors of parents navigating children with disabilities. Parents navigating children with invisible disabilities have their own set of challenges when interacting with individuals in society. For instance, mothers are often blamed for their child's invisible disability as they are normally the primary caregiver of the child. In addition, parents navigating children with hidden disabilities may come across school staff who do not believe that invisible disabilities exist and are reluctant to provide services and support to the child.

School staff can assist children with invisible disabilities by listening to the child when they express concerns and by trying to comply with 504 Plans and IEPs. If school staff have a question about the child's disability, contacting the parent to receive further clarification is a step in the right direction towards developing a relationship built on respect. School staff can assist parents with their child's navigation process by welcoming and inviting them into school buildings to be involved and engaged in their child's education.

Chapter 3: Methodology

I have a personal interest in learning more about the experiences of parents navigating children with invisible disabilities to high school graduation. In the first two chapters, I indicated that there is a large body of literature dedicated to the experiences of parents navigating children with physical disabilities, yet the experiences of parents navigating children with invisible disabilities are often not explored. This study showcased parents' reactions and experiences while interacting with school staff from the KPS district particularly at KCHS. It is my hope that this study will provide a voice to parents navigating children with invisible disabilities; share the challenges that they may have faced securing services for their child at KCHS; highlight parental involvement and engagement practices within the KPS district, particularly at KCHS; and offer suggestions of how parents and school staff can interact more effectively to build positive collaborative relationships at KCHS. In addition, this study sought to fill the gaps in the literature in relation to parents caring for children with invisible disabilities while showcasing parental experiences as they navigate their children towards high school graduation. The research sites for this study as follows: Kalamazoo, Michigan; Kalamazoo Public School; and Kalamazoo Central High School. The participants live in Kalamazoo, MI. Their children attend Kalamazoo Central High School a traditional high school within the Kalamazoo Public School district.

Kalamazoo, MI

The research sites for the study were Kalamazoo, Michigan, more specifically Kalamazoo Central High School (KCHS), which is part of the Kalamazoo Public School (KPS) district. Kalamazoo is situated in the southwest section of the state of Michigan. In 2010, Kalamazoo County had a total population of 261,654 people. The city of Kalamazoo had a

population of 74,262 residents (U.S. Census Bureau, 2010). An urban region is defined as an

area having a population of at least 50,000 people (Hall et al., 2006). Since Kalamazoo has a

population of over 50,000 people, the city is considered an urban region. Additionally, in

Kalamazoo, the average number of single parent households is 44.6%, while the median

household income $31,189 (U.S. Census Bureau, 2010). Large industrial or manufacturing

businesses are present in Kalamazoo. Upjohn, now known as Pfizer, was founded in Kalamazoo

and is its largest employer as well as a Fortune 500 company. Other industrial/manufacturing

businesses in Kalamazoo are the Stryker Corporation, Schupan Aluminum, and the Kalamazoo

Industries, Inc. (Kalamazoo, Michigan Business and Commerce/Manufacturers, 2017).

Kalamazoo Public School District and Kalamazoo Central High School

Kalamazoo Public Schools is the largest school district in Kalamazoo County. It is the

largest school district in southwest Michigan and the second largest on the west side of the state.

(Kalamazoo Public Schools, 2017). According to the Michigan School Data website's (2018),

during the 2016-2017 school year, a total of 12,934 students were enrolled in the KPS district.

The number of students in the district during the 2016-2017 school year who were counted as

having a disability was 1,646 students or 12.7% of the KPS student population. The school

district is comprised of 26 schools: 17 elementary, 5 middle, and 4 high---2 traditional and 2

alternative high schools. There are approximately 3,116 students attending the four high schools

(Kalamazoo Public Schools, 2017). In 2017, the KCHS population was 1,666 students (State of

Michigan, 2018).

The KPS district is afflicted with high poverty rates represented by free and reduced

lunch data (Russo, 2004). Twenty-one of the 26 schools that comprise the KPS school district

had free/reduced lunch rates at 50% or above during the 2016-2017 school year (State of

Michigan, 2018). In an article published in the school districts' online newspaper, Dr. Michael

Rice, KPS superintendent stated students from the KPS district are more economically

challenged than other students in the state of Michigan: "KPS students are also 50 percent poorer

than the state as the whole. While the rates of students on free or reduced-price lunch tend to

range 45 to 48 percent, KPS is typically in the 65 to 70 percent range" (Mah, 2018, p. 1).

Illustrations of Kalamazoo, MI, KPS District, and KCHS

Figure 1 represents the racial makeup of the city of Kalamazoo as follows: 68.1% White,

22.2% African American, 8.5% Native American, 6.4% Latino, 4.6% from two or more races,

2.8% from other races, and 1.7% Asian.
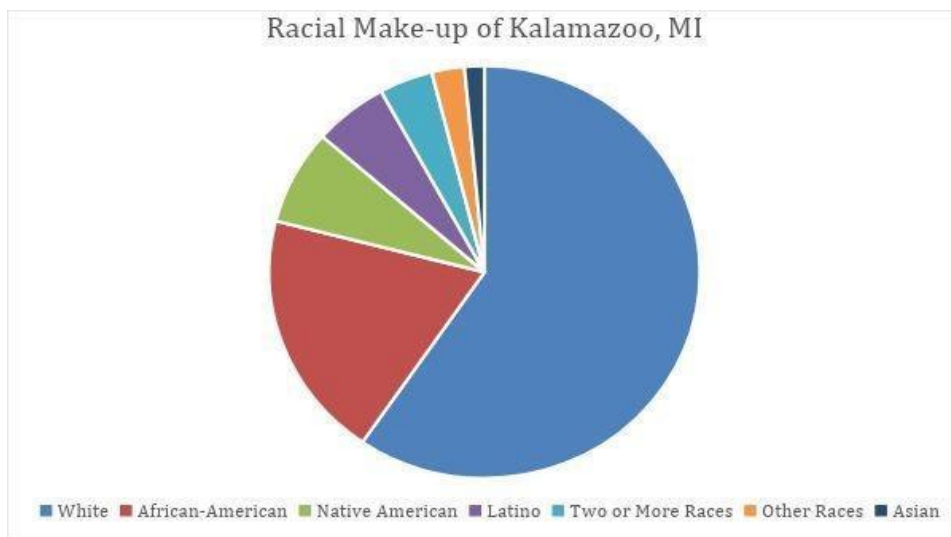
Figure 1. Racial makeup of Kalamazoo, MI.

The data from Figure 1 reveal that there are significantly more White people residing in

the city of Kalamazoo than any other racial group. Even though urban areas are becoming more

diverse, there is still a negative connotation with the word "urban." In many instances, the term,

urban, is associated with minorities dominating an area (Deslatte, 2015). Based on the

demographics of Kalamazoo, MI more Whites live in the city and yet it is classified as urban

based on population count.

Figure 2 illustrates the various age groups present in the Kalamazoo Community: 16-25, 37.7%; 26-45, 25%; 46-65, 25%; 66+, 12.3%.
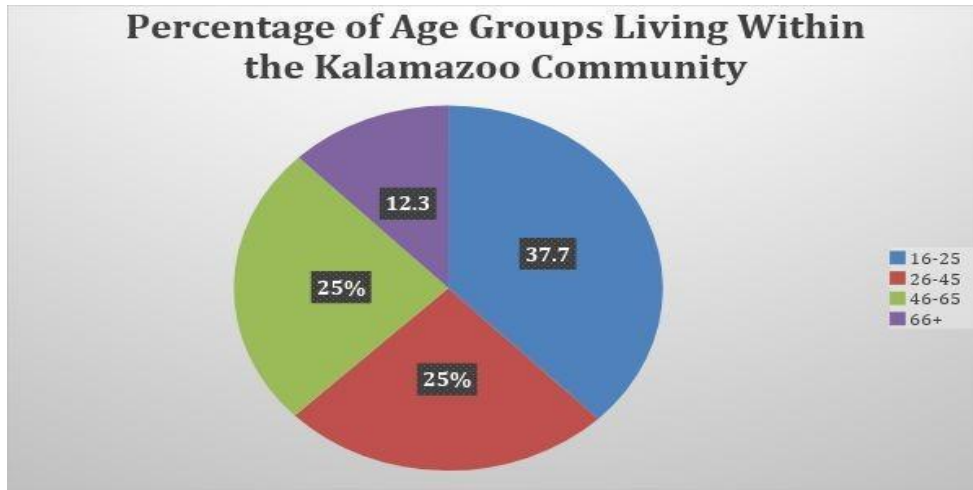
Figure 2. Percentage of age groups living within the Kalamazoo community.

The 16-25 age group is the largest in the Kalamazoo Community at 37.7% (U.S. Census Bureau, 2010). This age group traditionally attends high school and college.

Adult education levels, in Kalamazoo, MI, (Figure 3), are as follows: less than high school completion, 36.5%; high school completion, 14.7%; some college, 32.4%; and college completion, 16.4% (U.S. Census Bureau, 2010).
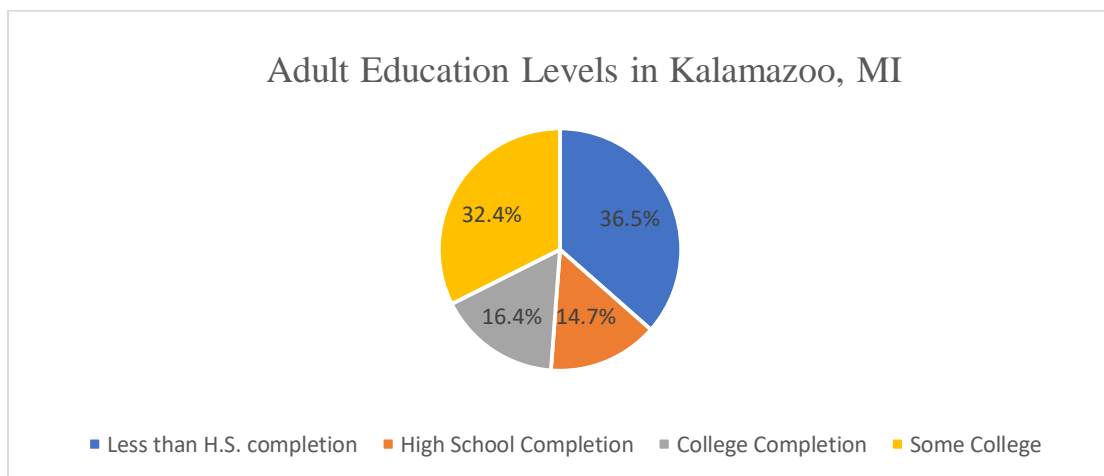
Figure 3. Adult educational levels in Kalamazoo, MI.

The data from Figure 3 showcase the education levels for adults in the city of Kalamazoo, MI. The data within this figure are noteworthy. The Kalamazoo Promise was established in 2005. In a community where students who graduate from a school district can possibly receive a free or discounted college education, only 16.4 % of the population possess a degree from a higher education institution (U.S. Census Bureau, 2010). One might assume that the percentage of individuals possessing college degrees would be higher in the city of Kalamazoo since students who graduate from the KPS district can benefit from the Kalamazoo Promise.

The data from Figure 4 highlight the number of students in high school who were counted as having a disability in the 2016-2017 school year.
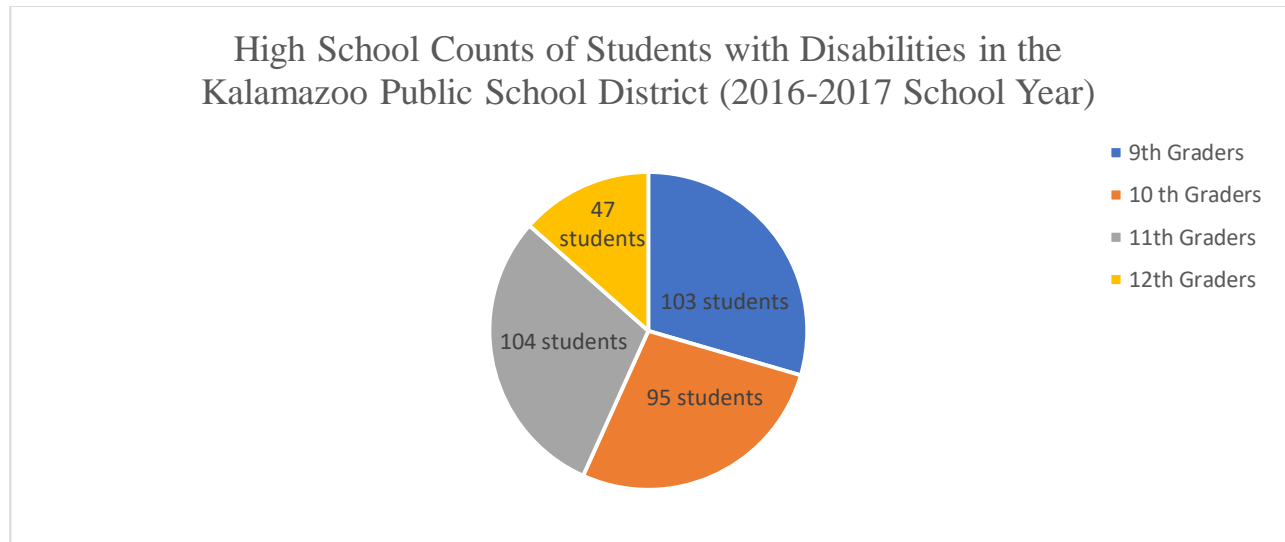
Figure 4. High school counts of students with disabilities in the Kalamazoo Public School District during the 2016-2017 school year.

In Grades 9-12, there were 349 students within the district receiving special education services. Eleventh graders represented the highest number of students in the district with an identified disability at 104 (State of Michigan, 2018). The number of 11th graders diagnosed with disabilities is significant. That is the year when students start seriously thinking about their

future after high school graduation. I was interested in learning if parent and school staff

interaction within the KPS district, specifically at KCHS, are collaborative and allow successful

navigation to take place for children with invisible disabilities during the late high school years

towards high school graduation. I was not able to locate the number of students with the KPS

district in Grades 9-12 that are diagnosed with invisible disabilities and have 504 Plans.

The data in Figure 5 showcase the race/ethnicity distribution at KCHS during the 2015-

2016 school year with a student population of 1,647 during the same school year (National

Center for Education Statistics, 2018).

Student Race/Ethnicity at KCHS 2015-2016 school year

- Amer. Indian; 0.002%
- Asian; 0.026%
- Black; 50%
- Hispanic; 0.091%
- Pac. Islander; 0.001%
- White; 32%
- Two or more Races; 0.060%
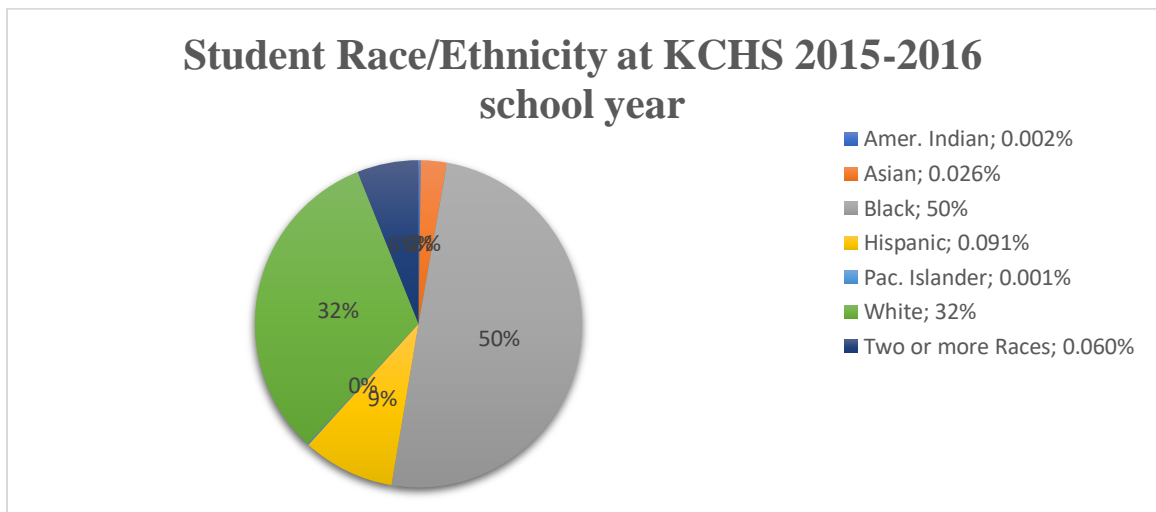
Figure 5. Student race/ethnicity at KCHS during the 2015-2016 school year.

Half of the student population during this school year was African American/Black

students. The student population, 50% African American/Black at KCHS is the opposite of the

overall city population of Kalamazoo, MI, in 2010. During the same year 2010, there were

68.1% White residents in the city limits of Kalamazoo. It is interesting that in a city where more

White residents are present, at KCHS, African American/Black students dominated the school

population.

The data in Figure 6 highlight the free and reduced lunch rates at KCHS during the 2015-2016 school year. As the chart below represents, over half of the student population at KCHS (55%) were eligible to receive free or reduced lunch (National Center for Education Statistics, 2018).
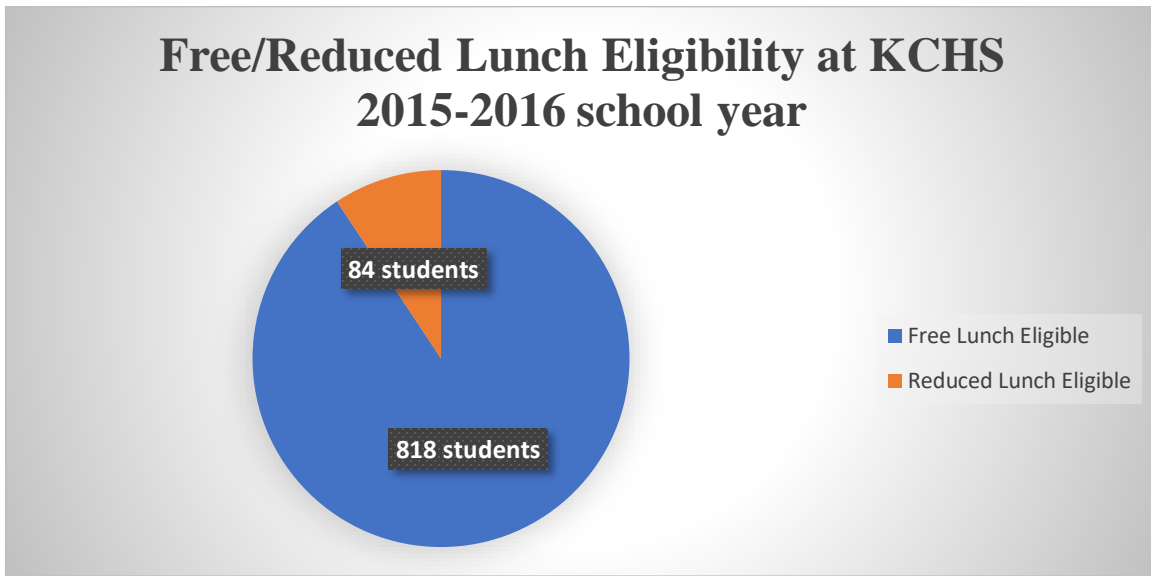
Figure 6. Free/reduced lunch eligibility at KCHS during the 2015-2016 school year.

The majority of the of the students represented in the chart were able to receive free lunch. The data from this chart is important because it shows the high poverty rate present within the KCHS student body.

Research Questions

The overarching research questions for this qualitative research study utilizing the case study method were as follows: How do parents illustrate their experiences within the Kalamazoo Public School District specifically at Kalamazoo Central High School, and how do they characterize their interactions with school staff while navigating their children with hidden disabilities toward high school completion?

Other questions that were asked include the following:

1. Do cultural/social differences between parents and KCHS school staff influence parent involvement/engagement in the school? How? If so, in what ways?

2. While seeking services for their children with invisible disabilities, during the late high school years at KCHS what experiences do parents report?

3. What interventions do parents perceive were the most helpful during their children's navigation to high school graduation during the late high school years?

4. What perceived gaps and omissions in services influenced their children's navigation to high school graduation?

This case study focused on the participants' children with a diagnosed invisible disability in the 11th or 12th grade and enrolled at KCHS, a traditional high school within the KPS district. This is the same school district my daughter attended during the first grade when she was diagnosed with an invisible disability and from which she eventually graduated high school.

Research Design

This qualitative research design employed the case study method, a method of design found in several areas of the social sciences. 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). 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. I also needed to be able to devote an adequate amount of time to analyzing each case to discover themes.

I chose to conduct a qualitative versus quantitative study because qualitative research more suitably presents the experiences of my participants in this instance. To conduct a sound qualitative study, the researcher should have familiarity with the investigation topic (Brantlinger et al., 2005; Sutton & Austin, 2015). My own personal experience with navigating a child with an invisible disability through the K-12 educational system to high school graduation assisted me during this study. Participants felt more comfortable sharing and allowing me to report their experiences due to the fact I have already been through this process with my own child.

Another reason I conducted a qualitative research study is that this form of research has an advantage over quantitative research in its ability to tell the stories of marginalized populations (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).

There were various goals of this study. I hoped the study would shed light on challenges that parents navigating children with invisible disabilities enrolled at a traditional urban high school during the late high school years may be experiencing and supply them with guidance on how to seek services and supports for their children. In addition, the study sought to uncover how parental involvement and engagement may affect a parents' experiences obtaining services for their child while interacting with school staff in an urban school setting. I also wish, ultimately, to educate school staff on how to interact and support parents navigating children

with invisible disabilities through the K-12 educational system to high school graduation. To

understand the experiences of parents navigating their children with invisible disabilities through

the K-12 educational system to high school graduation, four participants were selected to engage

in a qualitative study. A broad definition of qualitative research is "a systematic approach to

understanding qualities, or the essential nature of a phenomenon within a particular context"

(Brantlinger et al., 2005, p. 195). Qualitative research strives to better comprehend the views of

the individuals that the investigator wishes to study to gain an understanding of the complicated

experiences faced by the participants (Timmerman & Mulvill, 2015). Appendix A presents my

Human Subjects Approval letter which allowed me to conduct research on human participants.

Selection and Sampling Methods

Due to the large size (student population) of the KPS district, I determined that I would

focus my qualitative study on one traditional high school within the KPS district, KCHS. The

focus on one school shed light on how parents and school staff at one school interact when the

child has an invisible disability. The four participants were recruited in the following ways.

First, I posted flyers in various businesses that parents frequent (e.g., grocery stores, nail salons,

fitness clubs, churches) within a 10-mile radius of KCHS. Before posting any flyers in

businesses, I asked permission from the owner or manager. The flyer that I utilized to recruit my

research participants is featured in Appendix B. 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, I relied on participants to refer individuals who are a part of their social network

and familiar with the topic that I was trying to study. 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 parent participation in this study called for individuals to be a parent or guardian of a child with an invisible disability. The child had to attend KCHS 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. Informed consent is a method of ensuring that individuals understand what it means to participate in a research study. Furthermore, it allows them to determine if they would like to move forward with their involvement in the study. Informed consent is important to have from all research participants. The documentation signifies that the individual understands their role and rights as a participant in a research study (Mack et al., 2005). I acquired written consent from the participants who were selected for my study. I also provided a copy of the written consent form to my participants for their records and I will keep their consent form on file for documentation purposes. An example of the consent form signed by my research participants is displayed in Appendix C.

Data Collection Methods

In a qualitative study, interviews are often used as a method of data collection (Alshenqeeti, 2014). Interviews allow researchers to gain clear answers immediately while questioning participants. More specifically, semi-structured interviews are a more natural, universal format and are less structured than formal interviews. Semi-structured interviews provide an opportunity for researchers to probe and respond immediately to the interviewees' responses (Alshenqeeti, 2014; Hoepfl, 1997). This type of interview allows the participants to go off script and share information that is pertinent to the study that adds value to the data being

gathered. Participants can express their own thoughts and feelings on the research topic

(Alshenqeeti, 2014). Creswell (2014) proposed interviewing as a technique to uncover how

participants were individually ill-treated.

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. I hand-wrote notes during the participant interviews to capture their responses to my

questions. The questions that I asked my participants during their semi-structured interviews are

featured in Appendix D. Interviews were also audio taped and later transcribed. I listened to the

audio tapes repeatedly and compared what I heard to my written notes to develop common

themes. After the interviews, the audio tapes and notes were secured in a locked cabinet that

only I have access to. All the names of participants have been masked by pseudonyms to protect

identities. This was done to ensure that no retaliation can be taken against the parents/caregivers

or their children since they live in the community and attend KCHS, a school in the KPS district.

Member checking is a popular technique utilized in qualitative research (Birt, Scott,

Cavers, Campbell, & Walter, 2016; Creswell, 2014; Hoeplf, 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).

Besides attempting to make sure that I correctly interpreted what each participant expressed

previously in their individual interviews, a member check also helped to reduce any personal

bias that I may have as a researcher since I have experience with the subject matter (Birt et al.,

2016; Pugach, 2001).

I conducted two member checks with my participants. Within two weeks, participants were contacted via e-mail. I provided participants with a copy of their interview transcript. They had an opportunity to read and determine if I interpreted their answers to my questions correctly from their semi-structured interview. After I wrote Chapter 4: Findings, I provided the participants with a draft of their section. They were able to read the contents in a more polished format. Member checking may also increase the development of validity in the study (Birt et al., 2016; Harper & Cole, 2012). In qualitative research, the term "validity" means determining if the information gathered from the study is accurate and can be supported by evidence (Birt et al., 2016; Harper & Cole, 2012). The action of performing a member check does not mean that an investigation study will be credible. Credibility comes from an excellent recount of the participant's story as delivered (Birt et al., 2016). In this way, member checking facilitated credibility, reliability, and validity for my study.

Since I am conscious that I have a strong personal connection to the research topic, peer review was utilized to control for my personal bias on the research topic and to secure additional credibility. Peer review, or peer debriefing, involves having someone examine my data who understands the research topic but has no direct affiliation with my work (Anney, 2014; Creswell & Miller, 2000; Spall, 1998). These reviewers also assisted in ensuring credibility, reliability, and validity in my study's findings. Reviewers/debriefers are often associated with researchers in the following capacities: colleagues, classmates, and co-researchers (Spall, 1998). I solicited one of my professional colleagues to serve as my peer debriefer and review interview transcripts from my participants. When I provided my colleague with the participant interview transcripts, no identifying information was listed on the transcripts. She could not determine the identities of the participants from the information she examined. I selected this colleague to be my peer

debriefer for several reasons. My colleague is a licensed social worker with her own private practice. She conducts special education assessments for children through her practice. My colleague is familiar with invisible disabilities and works with school employees in order to secure IEPs and 504 Plans. Since she does not know any of the participants in the study, she provided unbiased feedback on the data that I collected although she is well-informed about my research topic. Obtaining a peer debriefer provides additional credibility to a research study (Anney, 2014; Creswell & Miller, 2000; Spall, 1998).

A follow-up interview was conducted with Participants 2 and 4. The follow-up interview allowed two of my participants to interact with each other around the shared experience of raising African American males with invisible disabilities who attend KCHS. Providing multiple occasions for research participants to be interviewed 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 E. I served as the facilitator of the follow-up interview session. In addition, the session was audio taped and later transcribed to uncover themes.

Since my sample size was small, I elected to conduct a document analysis to acquire extra material from my participants. Examining printed or electronic material to obtain supplemental information will enhance the value of the research (Bowen, 2009). A few examples of materials that are utilized for document analysis are background papers, letters, newspapers, diaries, and books (Bowen, 2009; Hoepfl, 1997). There are various reasons why

implementing document analysis into my qualitative research study was important. The technique can be utilized to gain triangulation which adds more credibility to a research study and to formulate additional questions that can be asked of participants (Bowen, 2009).

Analyzing more data helped me build a potentially stronger case around the examination of supports and services schools voluntarily provide to parents. In addition, parent involvement and engagement opportunities may not be easily accessible to them. My intention for requesting the 504 Plans and IEPs was to determine what supports or services parents with children with invisible disabilities are aware of in the KPS school district (KCHS) 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. I requested IEPs and 504 Plans from parents during the semi-structured interviews to conduct a document analysis. Participants 1's and 2's children still have IEPs. Participant 2 provided me with correspondence between herself and her son's IEP coordinator. Participants 3's son's 504 Plan was stopped by the school district at the end of elementary school, and Participant 4's brother was just recently 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.

Triangulation is another method to check the validity of a study (Birt et al., 2016; Creswell, 2014; Guion, Diehl, & McDonald, 2002). Triangulation refers to multiple methods to study the data (Birt et al., 2016; Creswell, 2014; Guion et al., 2002). There are various types of triangulation methods including data, investigator, theory, environmental, and methodological (Guion et al., 2002). I utilized methodological triangulation for this study. I collected data through multiple approaches: in-person, semi-structured interviews; member checks; and a follow-up interview with two of my study participants as well as document analysis. By

comparing the data gathered from the in-person interviews, member checks, follow-up interview, and document analysis, I determined if I interpreted my participant answers accurately. If they are, validity will be confirmed (Guion et al., 2002). The three data points examined during this study were semi-structured interviews/member checks, follow-up interview, and document analysis (information from Participant 2).

Limitations

The findings of this study were limited by various factors. I focused the participant search on parents navigating children with invisible disabilities. The participants' children were enrolled at KCHS, only one of the four high schools in the KPS district. My decision to conduct a study there is mostly based on location convenience. Children were either in the 11th or 12th grade. Late high school is generally when children prepare for high school graduation. I was interested in receiving recent feedback from case study subjects on their child's navigation though their K-12 education to high school graduation. In my 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.

Delimitations

I chose to conduct a research study on parents navigating children with invisible disabilities. The study did not include the parent experiences of navigating children with physical disabilities. There is already a substantial body of research available for this group, even though they are a marginalized population. There are many frameworks that I could have chosen for my study, but I decided on the EPE model. In my opinion, this framework best suited my study since it focuses on parental involvement and engagement within urban school districts.

Chapter Summary

To bring forth the experiences that parents are having or not having as they guide their children with invisible disabilities within the KPS district exclusively at KCHS, a qualitative study utilizing the case study method was conducted. Even though a quantitative study could have been done, my decision to conduct a qualitative study is based on recommendations from scholars such as Creswell (2007, 2014) and Patton (1990). A qualitative study allowed me to gather and analyze the data necessary to make suggestions on how parents and school staff can more efficiently work together in the best interests of children as they move towards high school graduation. Conducting a study with a small sample size aided in creating an intimate situation that allowed me to get to know my participants better. My personal experience with the KPS district, and KCHS specifically, and the topic of the study was helpful in gaining the trust of my participants. Data was collected through semi-structured, face-to-face interviews; member checking; a follow-up interview; and document analysis. Utilizing multiple data sources helped to determine if my study had triangulation and credibility and assisted in controlling my personal bias to the subject matter.

Chapter 4: Findings

I conducted a research study to explore how parents/guardians were navigating children with invisible disabilities. Their children were enrolled in the 11th or 12th grade at KCHS, a traditional high school that is a part of the KPS district. In the quest to answer the research questions, I recruited four participants who took part in individual semi-structured interviews and two participants attended a follow-up interview.

All the parents/guardians highlighted in this study are African American females raising African American males. I intended to solicit a wider range of participants, but their experience and expertise were still valuable in determining how parents/guardians raising children with invisible disabilities are navigating within the KPS district. The participants ranged in ages from 21 to 42 years old. This group included biological mothers and an older sister raising her two younger brothers after their mother passed away last year. The time frame within which children were diagnosed with their invisible disabilities ranged from birth to as recently as two months ago. The children possess a variety of invisible disabilities: ADHD, sensory disorder, crohn's disease, right cerebral maldevelopment, speech impediment, and diabetes. Quotes from the participants detail 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. Their quotes also presented the voices of female minority caregivers. They graciously provided a narrative of their children's journeys as well. All the names of the parents/guardians, their children, and KCHS staff identified during the semi-structured interviews and follow-up interview were protected by pseudonyms due to their association with KCHS and the fact they all live in the city of Kalamazoo. In the section below, the findings from the four participants during their individual, semi-structured interviews were presented. Parents/guardians furnished

their experiences navigating a child with an invisible disability. The parents/guardians also detailed their child's experiences interacting with KCHS staff in their late high school years. The participants' responses are arranged in the order that they were interviewed.

Marie

Marie is a 40-year-old African American female who is married with four children (one girl and three boys). Marie currently works as an accountant at a local business but has worked as a registered nurse in the past. All three of her sons have invisible disabilities. Her middle son, "Nick," was the focus of our interview. Nick is classified as a 12th grader at KCHS. When he was in early elementary school, Marie noticed issues with Nick's behavior. Nick was disruptive at school. According to Marie, his behavior was not "sporadic," but pretty much every day. He would lock himself in rooms and sometimes even leave the school building. Marie knew that something was wrong. Nick was diagnosed with ADHD and a sensory disorder in the 3rd grade. At that time, Nick was enrolled in another school district and an IEP was obtained. Marie and her family moved to Kalamazoo and Nick was enrolled at a middle school in the KPS district when he was in the 6th grade. His IEP transferred over. In 7th grade, Nick started to get sick. He had severe abdominal pains and episodes of diarrhea. After switching doctors, 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 our interview, Marie and I discussed the frequency of meeting with school staff to review Nick's IEP and whether the IEP was reviewed on a regular basis. Marie stated:

I initiate the meetings every year. If I don't follow through with it right away, I don't

hear anything. I don't think they make an initial effort in the beginning of the school year

to handle their IEPs. I always get with the staff at least during the first month of school.

I'm like this is important, let's get this done.

As Nick has gotten older, Marie stated that his behavior at school has matured: "He

definitely had behavioral issues that were affecting his schoolwork, his education, grades, and

attendance. His IEP continued because he was diagnosed with Crohn's disease. He is mature

now. He doesn't have the same behavior that he had in elementary school."

Even though Nick has matured he has had some issues at KCHS besides his Crohn's

disease. Nick's older brother has a permanent brain injury due to a car accident. Before Nick's

brother graduated from high school, other students attempted to physically assault him. A blow

to the head could have been fatal for him. Nick recognized that the incident was going to

escalate and stepped in in order to protect his brother. Consequently, Nick was almost expelled

from KCHS:

> He has had a couple of blow ups at Central. They tried to expel him. We had to go
>
> through an administrative hearing. But it was determined it was a manifestation of his
>
> disability. So, they let him come back to school. We fought for that though. They did
>
> not want him back in that school. I was like this is not even like his behavior. He has an
>
> emotional disability. For him to have that type of outburst, something had to have
>
> triggered it.

Nick's main issue now is his Crohn's disease and the amount of days that he missed from

school for treatment. During 9th grade, Marie described when Nick had to be hospitalized for an

extended amount of time for his Crohn's disease:

> Nick got sick. It was around the last day of school before Christmas Break. He
>
> was vomiting so bad. I went and picked him up from school. I took him right to the ER.

He was admitted to the hospital. He spent the whole entire Christmas break and

Christmas in the hospital. He got out the first week in January and because he had a pic

line, KCHS would not let him come back to school. They said we do not have a school

nurse here to handle someone carrying around a pump; they wouldn't do it. I was like

ok, but at the same time I had the pediatric gastroenterologist send paperwork to the

school stating Nick was hospitalized, he has a pic line and was released to come back to

school. Rather than making an adjustment they failed him. They gave him all Fs.

After KPS decided that they would not be able to accommodate Nick with a pic line even

though medical staff released him to come back to school, KCHS and the KPS did not provide

Marie and Nick with an alternative for him to keep up and not get further behind in his school

work (i.e., Home Bound schooling). During our interview, Marie stated Nick still had an active

IEP. Marie listed some of his individual accommodations:

He is supposed to get shortened book assignments, limited homework, additional time for

work. If he is out of school for anything associated with Crohn's disease his absences are

supposed to be excused, and they won't. He missed days and they wouldn't give him his

missing work, or he wouldn't get the work done and then it was a bunch of Fs. Marie

also stated that Nick was only supposed to be assigned the standard curriculum work.

Even though his IEP specifies the type of assignment he was expected to complete, he

was being given assignments that he should not have been asked to do: "They were failing him

on work that he should not have even been assigned."

A question that I posed to Marie was, "Do you feel like school staff follow the

goals/services stated in Nick's IEP?" She stated:

They don't follow his accommodations at all. And I know they don't, because he is

supposed to have shortened work assignments, he is only supposed to have the standard

curriculum work. They were giving him work that was not even supposed to be assigned.

They were failing him on work that should not have even be assigned to him. No matter

what he did he was not getting ahead, Nick got so overwhelmed. We talked and he said

he didn't understand because he was doing everything he could do, and he was still

failing.

Before our interview in early December 2018, Marie mentioned that Nick met with his

school guidance counselor to get assistance with figuring out how he could get caught up on his

schoolwork. Instead, he was told he would not be graduating on time with his class. He was

given the option to finish the rest of his senior year at KCHS knowing that he was not going to

be able to graduate or even walk with his class and then transfer to Phoenix High School (an

alternative high school within the KPS district with no Special Education Services):

He met with the counselor for help and they told him basically you don't have enough

credits to be here. You should just go to Phoenix. Who tells a child that? He was crying

and saying that I don't belong here, I'm not smart. He said you and dad tell me that I am

smart, but everyone at the school thinks I'm stupid mom.

So, Nick is a 12 grader with probably 12 credits. They were like you can stay

here the rest of your senior year and at the end of the year you can go to the Transitional

School Program or enroll at Phoenix. That's the best they could offer him, Why would I

move him to Phoenix when he is struggling here with accommodations? Phoenix doesn't

have the staff to accommodate Special Education Services. They were like well, he

won't need as many credits. That was basically their attitude.

Towards the end of our interview, Marie stated that she was going to support the decision that Nick was going to make---staying at KCHS and transferring to Phoenix at the end of the school year or getting a Graduate Equivalency Diploma (GED). She just wanted what was best for him. I asked Marie if she felt like she and her son's treatment was related to race. She was very candid that she does not feel like the 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. But you know what? Those 400 kids who are struggling are the ones that need help over the 600 that are doing good. You know, I think they get lost in the school system. I am not saying anything bad about teachers, but when you are disrespected or abused by the students you eventually probably do lose some of that desire to teach. You probably don't feel like you are helping. And I think some of these kids that have behavior problems, teachers are tired of dealing with kids like that, so they don't; they are just showing up at school. That's how I feel, so I don't think its race. We haven't had support by the White staff or the Black staff for that matter. So, no I don't think it's racial at all. 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.

Side note. Marie and I talked in early January 2019. She was invited to interact with the other research participants. She called to let me know why she was unable to attend. Nick had to be hospitalized due to his Crohn's disease. During our conversation she mentioned that she

had received a phone call earlier in the day from a KCHS staff person. They called to inquire if she and Nick had decided whether he was going to stay at KCHS and then transfer to Phoenix High School, the alternative high school, at the end of the school year and about the amount of days Nick had missed from school. Marie let the KCHS staff person know that Nick decided to pursue his GED through another school district. Marie stated that the response from the KCHS staff person was cut and dried: "Ok, thanks for letting us know, and then they hung up. They didn't even fight to keep him there." Due to their quick response, Marie feels like Nick never mattered to the school. Nick feels as though the school no longer wanted him there and they gave up on him. Marie no longer has faith in IEPs, or services put in place to assist children with invisibles disabilities or "maybe just no faith in KPS."

Roshawn

Roshawn is a 42-year-old African American female. She is married with six children. Roshawn and her husband moved to Kalamazoo in 2006 from Washington State so their children could take advantage of the Kalamazoo Promise. Roshawn is currently a business owner, but in the past, she has 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. Cairo is currently in the 11th grade at KCHS with an active IEP.

During our interview Roshawn stated, "pretty much at birth" they 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-years-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 6th grade, Roshawn decided to secure a formal IEP.

> Sixth grade was when I took it to the next level to get help. But he was really diagnosed at birth. But I just maintained it. In 6th grade they called it ADHD. But at birth they called it Right Cerebral Maldevelopment. But it stems from the same issue.
>
> We managed through the elementary years but by 6th grade it became a little much as far as the attention span, staying focused and his grades. So, I took him to a doctor to get him officially diagnosed in the 6th grade.

Roshawn worked for a local non-profit agency that supports individuals with disabilities when she decided that Cairo could benefit from an IEP. One of her colleagues helps parents become knowledgeable about the services and accommodations that can be written into their child's IEPs. Roshawn sought help from this colleague in securing an IEP for Cairo:

> We did a workshop together for my job. Then I made a separate personal appointment with her. I let her know I wanted to get started with getting Cairo an IEP. I connected with her to help me write the IEP and what I should look for, and what I should be asking for in the meeting. She gave me the 411. I had that information. I started off by writing a letter to the principal and the school psychologist and let them know these are my concerns and I want to start the process of setting up a meeting for an IEP. So that's how I got the ball rolling. I knew from talking to the professional that they have so many days to respond. I waited for the response, then the next step if it was a minute past the due date I was following up with another letter. You know you didn't respond within in 30

days. And I think I did have to send that letter like you didn't respond. So, they said we

promise next week we will respond. That's how I initiated the process.

When Roshawn went to Cairo's first IEP meeting she also brought an advocate with her

from ASK Family Services (a non-profit agency that supports children with disabilities and their

families): "I contacted ASK. At the very first IEP an ASK representative was with me during the

meeting. They gave me ideas of what I should say and just kind of helped me navigate that new

territory and difficult waters." Since Cairo has an active IEP Roshawn and I discussed whether it

is reviewed and amended on a regular basis:

> It sure is! I guess you redo it every three years but its reviewed annually. I think
>
> probably about a year and a half I submitted an amendment because I wanted to add more
>
> things. I realized what I had was ok, but the IEP needed to be beefed up. I added
>
> probably about 20 more things to the IEP. I know they were probably thinking where
>
> this girl gets this information from, but I was informed. I had the information.

Some of the things that Roshawn added to Cairo's IEP were breaking up his homework,

being able to have an item in his hand for fidgeting purposes, taking breaks more often, and

testing in a quiet environment. When it came time to amend Cairo's IEP, KCHS staff even

adjusted their schedule to accommodate Roshawn's busy life as a business owner:

> They know I am a busy individual and I travel a lot. They knew the IEP review was
>
> coming up in March. They emailed me in January to get on the calendar so we can be
>
> ready to rock and roll in March. They accommodated my schedule so we could be ahead
>
> of the game. They did that for me, and they didn't have too.

Even though Cairo is eligible for 80% of the Kalamazoo Promise, Roshawn and her

husband have decided that it would be best to enroll Cairo in a program that will help him

transition into college life first. He is going to the Michigan Career Technical Institute (MCTI), a trade school with dorms, once he graduates from KCHS. The program is a free and run through the Michigan Rehabilitation Services (MRS) which is a state office. Roshawn found out about this program from her old job at the non-profit organization. Signing individuals up for this service is one of the things that she used to do for her clients:

> I knew what was offered in my profession. Once I took my professional hat off at home, I called MRS and said I need my son signed up for your program. All the stuff that was available I knew all the steps. I knew how to do it, how to navigate the path because I did it on my job.
>
> For my son, this is going to be a great first step. We want to softly transition him. He is not the type I think that would do well going from home to a four-year university with dorms and just be like good luck. So, we are going to go through MCTI first to test it out and have him get used to that independent living before we transfer him to a four-year university.

Towards the end of our interview, I asked Roshawn if she had any closing statements that she would like to share with parents/guardians raising children with invisible disabilities. She stressed the point that parents raising children with disabilities need to be informed:

> Yes, you know what? It is super, super important for parents to be informed. I had some extra tools in my toolbelt, because of my job role at the time. But I know that that is not the everyone's situation. If you don't know ask questions, ask questions, ask questions! Because it is a lot of things they are not going to come forth and tell you. I went to them with all the information. This is what I want, this is what I need, and here is my 50-step plan, and let's start the process. But that's not the case for everyone.

There are a lot of non-profit organizations that provide free help and services that will help you be informed. The IEP process can be a lengthy complex process and frustrating as well. I really encourage parents to be informed. If you don't know something dig, dig, dig, and ask questions.

Side Note. During the semi-structured interview, I asked Roshawn if she would mind sending me a copy of Cairo's most current IEP. Roshawn sent me an e-mail later stating that she could not find the latest IEP. The family had recently moved, and she was unable to locate the document. She did send me e-mail correspondence between herself and Cairo's IEP coordinator, Ms. Stevens, who also happens to be the department head of the special education department at KCHS. Roshawn wanted to add 15 additional items to the IEP document. Some of the items that Roshawn wanted to add were the following: Cairo having a book or planner for class and homework assignments, the use of sensory tools, and that he be allowed to take tests at a specific time of day. Based on the responses from Ms. Stevens you could tell that she read the items from Roshawn thoroughly. If she thought an item was not needed, she compromised with Roshawn or came up with other options. For instance, Ms. Stevens stated that a planner would be provided for Cairo, but until he got it, she suggested Cairo log into the district online grading website to remind himself of the assignments that had been assigned that day along with due dates. Regarding the sensory tools, she requested that the school psychologist work with Cairo during their sessions. She also suggested a strategy to track whether the sensory tools were effective and utilized correctly. Lastly, for testing she suggested adding the words, "time that's beneficial" instead of specific time of day. Her reasoning was if there was a time of day that worked best for him, he could be tested during that time frame.

Latrice

Latrice is a 36-year-old African American female. 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, is a 17-year-old 11th grader at KCHS. Justin was diagnosed with a speech impediment when he was 4-years-old while he was attending Head Start. Latrice and I discussed how Head Start approached and broke the news to her that Justin had a speech impediment:

> Well I will be honest with you. I was blind to the fact he had an issue. It wasn't until
>
> Head Start brought it to my attention, with the services they have, the testing that they do
>
> with the kids. I just thought maybe it was a medical problem that he was not speaking.
>
> This led us to following up and discovering he has a speech problem. I was in complete
>
> shock. I was like there is nothing wrong with my child. First, I was in denial stage about
>
> him having any type of disability. Once they described it to me, they also started
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> showing me what he could and could not do when he was speaking. They pointed out
>
> how he would mispronounce words, slurring words together. Or when he would get
>
> frustrated, he just wouldn't talk. He would just completely shut down.

The Head Start staff helped Latrice secure a 504 Plan for Justin while he attended their program. They made obtaining a 504 Plan a painless process for her:

> It was simple, easy and straight forward. I didn't have to do anything. The speech
>
> pathologist met with him. It started off every day they met with him. And as the years
>
> went on it went down to one day a week. Consistently for the first five years, the speech
>
> pathologist met with him daily 20 minutes sometimes 30-minute sessions with other
>
> students. There were sessions when they even involved me at one point. They provided

me with handouts, they gave me good tips and suggestions on how to continue to help him progress. It was a very simple easy process for me.

Once Justin graduated from Head Start, they took care of transferring his 504 Plan to the elementary school that he attended. When Justin transitioned to elementary school, Latrice let teachers know that he had a 504 Plan and asked them to familiarize themselves with the accommodations outlined in the document. From Head Start to elementary school, Justin was able to work with the same speech pathologist:

> Yes, the 504 Plan followed him. When I would go to meet and greets at the beginning of the school year the teachers would ask if there were any special accommodations. Sometimes teachers would know and sometimes they didn't know. So, I would just always make sure I would bring his 504 Plan to the teacher's attention; have them go back and look at his file. One thing I did love is he had consistency. Mr. Benson (speech pathologist) went with him from Head Start to 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 though the 504 Plan:

> The 504 Plan stopped when he transitioned from elementary to middle school. I wanted him to participate in the services, but they said no. I was told he was no longer eligible for those services. They said he was up to par, based on the structure and systems that had been in place, and the charts they were going by, and the length of services that he received they no longer felt like it was necessary.

Even though Justin no longer has the 504 Plan, his speech impediment has not gone away completely. Latrice has come up with alternative ways to provide services and supports for

Justin. She has enrolled him in various activities. For instance, in middle school Justin was a part of an after-school program through Communities In Schools of Kalamazoo (CIS). CIS is a non-profit agency that partners with KPS. She also enrolled him in a mentoring program at a local church. He got a job as a peer educator with younger children in the community through a non-profit agency:

> No, he is not seeing anyone formally. He has not seen anyone since he transitioned from elementary to middle school. Now what I did do is I put him in after school programs and activities to get him more comfortable with speaking in front of people. In middle school, I enrolled him in an after-school program through Communities In Schools of Kalamazoo. Justin worked with the After-School Coordinator (ASC) of the program. The ASC helped Justin with his speech in informal ways. He was a very big supporter of my son.

> I signed him up to do different speaking engagements at Christian Life Center Church and through Western Michigan University Saturday sports and education program called The Wire. He was also a Peer Educator to younger children through another non-profit organization. I described to them how he struggles with speaking in front of other people. So, I just put him out there so he would get more comfortable. He also just did a big speech for Christian Life Center. He struggled a bit, but once again I was still there to support him all the way through.

Now Justin relies mainly on his cell phone and audio books to assist him with his speech. He can listen to the words on his phone and repeat them. Technology is giving him independence. He does not have to rely solely on Latrice to help him sound out words:

Sometimes he struggles to pronounce words in class. With technology today, it has really

come a long way. I can pull words on his iPhone, type the word in and ask his phone to

pronounce the word. He can hear it and say it. That's made him more comfortable.

Now he does not always to have to rely on me. Having audio books, being able to listen

to words, makes it easier for a child with a speech impediment. They can hear words

instead of constantly asking other people how to do you say this? Sometimes it is

embarrassing for him when he can't pronounce certain words. He has expressed that to

me. He is like this is awesome having this technology. Because again he is in high

school, he still struggles using words outside of his vocabulary.

Since Justin has continued to do well academically without his 504 Plan throughout his

secondary schooling, Latrice has not tried to secure another one. Per Latrice, Justin has been an

honor student ever since he started receiving letter grades:

His learning was never affected. The only disability was when he had to speak out loud,

he would shut down or not want to speak. In high school I have never expressed anything

to any of his teachers about his speech impediment, so I don't even think they know.

When they get to high school, they really don't involve parents that much. They have so

many teachers. You really don't have that time to express to them one on one

conversations like you can in pre-k through elementary. Once he got to middle school,

they stopped his speech. And I really did not have a chance to talk to every single

teacher and say he has this disability. At that point the 504 Plan was done, so they really

didn't care, I wasn't going to try to get the 504 Plan started again.

Towards the end of our interview I asked Latrice what advice she would give to other

parents raising a child with an invisible disability:

Some advice I would give is I started off being in denial. I think the first step is not being in denial that your child may need services. I think as parents we all want to think we have perfect kids and think nothing is wrong with them. So, once you get over that denial stage, find someone that can help support you as a parent. I made sure I had a support system in place. Once I had that support system, then putting a plan in place for him made it easier for me to follow through with the plan. So, I could support my child the way I needed too.

I encourage any parent whose child has a disability just to be knowledgeable about the disability. The more you know, the easier it is to work with your child. It was frustrating. At first, I thought it was normal that my child wasn't talking. You always hear people say boys are always slower than girls. I think I just didn't pay attention. The most important part is pay attention to your child. I am an involved parent, but I guess I didn't hone in on the little things. I just thought it was normal. And then not to mention I was a young mother. So, I really didn't know. He is my oldest child.

Side note. Latrice was unable to attend the gathering that I had invited her to with the other participants. On the day that of the event, Latrice was traveling back to town with Justin from a basketball tournament. We were unable to get a WI-FI connection in order to skype or call Latrice so she could be present remotely. I sent Latrice the questions that I asked the other participants during follow-up interview and she e-mailed her responses back to me. Latrice vividly defines parental involvement as "parent-reported participation at least three or more times during the school year." She listed examples of parent engagement activities as "attending a general school meeting, attending a scheduled parent teacher conference, attending a school or class event, or volunteering in the school or serving on a school committee." Latrice feels like

she is an involved parent. She stated that she serves in the following capacities: "a part of the

PTO, Coordinator of the Concession Stand, and the General Volunteer for Donations." Both of

her older children are involved in sports. Justin plays basketball, and her daughter is on the

cheer team. She stated that the school keeps her involved with situations pertaining to her son.

Since Justin has been in high school, he has not had any discipline issues. I concluded that

Latrice's experience with parental involvement is different than the other parents/guardians who

participated in the study. Her children are athletes, and Justin has not had any discipline issues

in high school. Finally, even though Justin is an honor student Latrice does not feel like KCHS

is preparing her son to take advantage of the Kalamazoo Promise.

Jenee

Jenee is a 21-year-old African American female who is raising her two younger brothers

who are both students at KCHS. Jenee has been raising her brothers for a year since the death of

their mother from complications of diabetes. Gavin is a 16-year-old 11th grader at KCHS. Gavin

was diagnosed with diabetes about two months ago. Since the diagnosis is so recent, a 504 Plan

has not been drafted yet, but Gavin is 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:

> I gave them the paperwork that stated he has diabetes. The school wanted me to give
>
> them more information. I told them that I couldn't until we went to the next doctor's
>
> appointment. I don't have any more additional paperwork to give you. At one point they

wanted me to bring in supplies. We got that taken care of now. Once I provided them
with everything they needed, things have eased up. The school nurse and I are on the
same page. It is not even the medical people at the school. It was other people who
know nothing about the situation.

Besides recognizing that Gavin really has an invisible disability, the school nurse also informed
Jenee of accommodations her brother is eligible to receive at KCHS: "The school nurse is the
one who talked to me about a 504 Plan." Some of Gavin's accommodations are being able to
leave his first hour class 15 minutes early to check his blood sugar, he can eat snacks if needed
and he is allowed unlimited passes to use the bathroom. According to Jenee, sometimes if his
blood sugar is low, he gets dehydrated and must go to the bathroom more often.

The school nurse even took things a step further and accompanied Jenee and Gavin to
one of his doctor's appointments and wrote down everything that the doctor said. The school
nurse then gave the information to KCHS staff, including to Gavin's teachers:

The last time I talked to the school nurse we were at the doctor's appointment. She wrote
down the information as the doctor was talking. She said she was going to write up a
report and give it to the school staff. Gavin was worried about that. He wanted to make
sure his teachers were aware of why he needs to go to the bathroom more often. She said
that she would make sure that all his teachers knew.

Gavin also takes medication at KCHS. When the school nurse is not present at the
school, it has been arranged for him to get his blood sugar checked by one of the school
secretaries: "He also takes insulin after lunch at school and after all his meals." Until Gavin's
formal 504 Plan is drafted, KCHS staff have been providing his accommodations. The school
nurse was instrumental in ensuring that Gavin's needs are being met at the school.

Follow-up Interview

All the participants were invited to participate in a focus group. My intention was to bring all the participants together at the same time and gather additional information from them interacting to utilize in my research study. Since all of the participants were not able to attend the event, 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. We pre-arranged for her to be skyped in via conference call or to participate on speaker phone but were never able to get a WI-FI connection. As a researcher, I am aware that it is not the same as interacting with the other participants, but Latrice answered additional questions and returned them to me via e-mail. Participant 2, Roshawn, and Participant 4, Jenee, were both present for the follow-up interview. During the follow-up interview participants were asked a series of questions. Their answers detailed who they felt helped them get their child's needs met. In addition, the follow-up interview also provided participants the opportunity to voice their opinions on various topics. Please see the participant responses to the following questions:

> **Reflect on an instance when a KCHS staff person helped your child during the late high school years. Describe what they did or said.** According to Roshawn, One instance that I can think of was when Cairo had a big project. With him I do have to take the bigger project and break it into small, small steps so we can get all 10 small steps done, which means the whole project gets completed. It was one project that was a physical project with popsicle sticks. We got some for the project and some kind of way they go wet and were destroyed. It pushed him back, so he got all frustrated. By the time he talked to his teacher about it he wanted to give up and just shut down. So, she gave

him a pep talk. She gave him more time to complete the project, even though it was past the due date. She gave him the mental time to redo everything that seemed destroyed. She gave him the time he needed to finish the project and turn it in. That was helpful because he wouldn't have turned it in. It would have been forget this, I tried, I flunked, and oh well. I have to tell him ok let's not do that, lets reflect.

Jenee said: I would have to say that a lady that works at KCHS named Mrs. Young has helped my brother. She called me because Gavin was not coming to school and he was missing days. It was around the time he was first diagnosed with diabetes. She set up a meeting for all three of us to meet and talk. It felt real and genuine. She made me feel like she really cared about what was going on with my brother. During our meeting, I found out what was really going on with my brother. Gavin let us know the reason he was skipping school was because he was scared. I found out my brother was just scared about his diagnosis, having to go to school and now take medicine. At that time the school did not have his medicine. So, he was just scared. Now everything is straightened out. I really appreciate her taking the time to call me because she did not have to do that.

Do you feel like you are an involved parent? Both Roshawn and Jenee feel like they are involved parents though and responded quickly if there were issues with their children. Roshawn described her involvement: I am a phone call or an email away and they know that. A lot of times they threaten my son, with well if you don't do this, we will have a conversation with your mom, or we are going to call your mom. He will be like no don't call my mom. By the time I get a call about him or from him I know that things have gotten bad. At the beginning of the school year what I do every time,

particularly with him because I have six kids. I try to do it with everybody, but he is the first on the list. I email all his teachers to let them know I am available at any time via phone or e-mail. Do not hesitate to call me. I welcome phone calls. So, they know, they can call. I open that door early and often.

Jenee responded: Yes, I feel like I am an involved parent. I try to make sure I have a relationship with everyone who is involved with my brother at the school and make sure we are all on the same page.

Which services/accommodations by KPS (KCHS staff) have been provided to your child during the late high school years. Roshawn replied: More time on tests, headphones if necessary, less homework that the rest of the group, more breaks if needed. Seating that is best suited for his learning style. And some of the classrooms have a second teacher that provides that extra assistance. They kind of help him a little bit. I don't know how often he takes the extra help.

Jenee described her brother's accommodations for his diabetes: He can go to the bathroom whenever he needs to because he gets dehydrated. He also needs to drink more water, so he carries around a bottle of water. Snacks for him just in case his sugar gets too low, and he gets to leave 15 minutes early from his first hour class to check his blood sugar.

Do you feel like their services are helping them move towards graduation? Roshawn said she is trying to meet short-term goals first: Maybe not in the long shot no. It is just helping him get through the next homework assignment the next class. It is very short-sighted. By the time he gets through all of that then he will get to his goal. But in a

comprehensive manner it is not preparing him to graduate. It is more tedious tasks, but not in the big picture no.

Jenee responded: I would say yes. It makes him feel more comfortable they are letting him do these things. I think if he is comfortable, he can focus better.

Do you feel like KCHS staff is preparing your child to take advantage of the Kalamazoo Promise? Roshawn didn't think so: They are not because it's about teaching you how to answer these questions correctly not teaching you how to process, problem solve these questions. They teach you this is going to be A, B, C. Ready go A, B, C. What are the answers? That's what they teach. How to pass the tests, not how-to problem solves, navigate so if I have questions like this on this test, I can use the same problem, solving skills over here. It is memorization. It does not prepare you. But kids that are academically advanced, they naturally have those problem-solving skills to figure out the problems anyway. It is definitely not taught or not taught very well. And so, the low standard academic students, they are so at the borderline. It is like, ok, look we just need you to memorize this, to pass this test, so we can get up and say we did it. By then students will go to the next grade and still be struggling. So, no there is room for growth and development.

Jenee agreed: I would say no. Honestly, with my brother, I think they are just passing him along. I am not sure he even knows what they Kalamazoo Promise is, so no.

Chapter Summary

Four participants were selected to partake in semi-structured one-on-one interviews where their experiences of navigating a child with invisible disabilities at KCHS, a traditional high school within the KPS district, were explored. The participants also provided insight into

their child's experiences through their narratives. All the interviews were audio recorded and the

notes were later transcribed and coded. The commonality that surfaced between the participants

experiences after analyzing the data from the one-on-one interviews were social connections.

All the participants except one were able to name individuals either at KCHS 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 KCHS or in the community are currently on track to graduate from high

school on time.

Roshawn and Jenee participated in a follow-up interview. The follow-up interview was

also audio-recorded, and data were later transcribed and coded. Even with the social connections

that have been built between participants and certain KCHS staff, participants reported

discouraging occurrences that have stalled their involvement in their child's education. Roshawn

and Jenee cited feeling unwelcomed when they walk through the doors of KCHS, 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 KCHS staff.

Even with feeling slighted, Roshawn and Jenee continue to be involved and want to be involved

beyond the occasional calls in relation to their child's behavior and to schedule IEP meetings.

Chapter 5: Implications and Suggestions

In Chapter 4, the findings of my research study were presented. One participant's child was not on track to graduate high school this year. During the follow-up interview, Participants 2 and 4 recounted challenges with interacting with KCHS staff. To explain the occurrences happening at KCHS between school staff and parents/guardians navigating children with invisible disabilities within an urban high school, the conceptual framework EPE was utilized. The EPE framework was discussed in Chapters 1 and 2. The framework has several components. The EPE framework explains how parents in urban elementary schools can position themselves utilizing the capital available to them despite cultural differences that may be present between school staff and parents. Furthermore, the framework indicates the differences between parental involvement and parental engagement (Barton et al., 2004). Besides the EPE framework, the teachings of Pierre Bourdieu, specifically his analysis of social capital, was utilized. This chapter contains an overview of the information that was gathered, examined, and ultimately grouped into themes during semi-instructed interviews and follow-up interview. Suggestions from participants to KCHS/KPS staff and researcher suggestions to KCHS/KPS and parents are provided as well.

The dominant theme that tied the participants' experiences together surfaced after analyzing the data from the semi-structured one on one individual interviews---social connections or the lack thereof. The parents/guardians' ability to develop relationships with school staff and community organizations helped determine whether a child was receiving accommodations/services and on track to graduate high school. When these relationships were not present, parents/guardians were not able to get their child's needs addressed and ultimately the children were not graduating high school nor taking advantage of the Kalamazoo Promise.

Themes that surfaced during the follow-up interview were parents not feeling welcomed when they enter the doors of KCHS, parents/guardians not being invited to participate in school events, cultural/social insensitivity by some KCHS staff, and lack of follow through by some KCHS staff members (i.e., special education teacher and main office front desk staff) in relation to communicating with parents/guardians.

Various Forms of Capital

In the literature, Pierre Bourdieu is highly regarded for his work on various types of capital (Gauntlett, 2011). Bourdieu was a French sociologist who was mainly known for his interpretation of social capital but provided insight on other types of capital (Gauntlett, 2011). In his 1986 work, *The Forms of Capital*, Bourdieu defined capital as:

> accumulated labor (in its materialized form or its 'incorporated', embodied form) which, when appropriated on a private, i.e., exclusive basis by agents of groups of agents, enables them appropriate social energy in the form of reified or living labor. (p. 241)

He later was more specific and described three forms of capital, economic, cultural, and social, and how these forms of capital affect people's lives. Bourdieu (1986) concluded the following when detailing the three forms of capital: economic capital (wealth, assets), cultural capital (educational advancement, expertise), and social capital (social connections, social network, and memberships to organizations. If executed properly, a person can combine social capital and cultural capital to achieve economic capital.

Bourdieu and Social Capital

The notion of social capital has been a topic of discussion in the field of social science for some time (Gudmundsson & Mikiewicz, 2012; Tzanakis, 2013). Bourdieu (1986) defined social capital as:

the aggregate of the actual or potential resources which are linked to possession of a

durable network of more or less institutionalized relationships of mutual acquaintance

and recognition-or in other words, to membership in a group. (p. 248)

Utilizing a network of people to advance and achieve goals is essential to Bourdieu's

interpretation of social capital (Bourdieu, 1986; Wilson, 2015). The size of a person's network

of connections can affect other forms of capital. Social capital can occur consciously or

unconsciously in the form of "gifts, services, words, time, attention, care, or concern" (Ihlen,

2005, p. 495). I decided to utilize Bourdieu in addition to the EPE framework after the semi-

structured interviews were conducted. After analyzing the data from the semi-structured

interviews, it was apparent that social capital (social networks) made the difference in the

participants' children's needs being met and whether they were on track to graduate high school

or not. Moreover, Bourdieu's work is utilized heavily in educational settings to explain how

marginalized populations can make use of capital to position themselves in order to achieve their

goals (O'Brien & Fathaigh, 2005).

Social Capital and My Research Participants

After the completion of the individual, semi-structured interviews, one major theme stood

out after analyzing the data. During her one-on-one interview, Marie did not indicate at least one

consistent person either at KCHS 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 KCHS and in the community has made the difference in her child's

not graduating on time. Unfortunately for Marie and her son, the harsh reality of the old saying

"It is not what you know, but who you know" turned out to be true (Guantlett, 2011). I spoke to

Marie in early January 2019. Nick made the decision to go to another school district to obtain

his GED. Marie supports her son's decision, and Nick will forfeit the Kalamazoo Promise once he leaves the KPS district. During our conversation, Marie shared with me that she received a phone call from KCHS staff earlier that day. They were inquiring about the number of days that Nick had missed from school and if he was going to transfer to an alternative school within the district with no special education services. Marie informed the staff person that Nick decided to leave KPS and obtain his GED from another school district. Marie stated that the person just said ok and hung up the phone. There were no further questions asked or discussion about the possibility of Nick's staying at KCHS. Their quick response made Marie feel like they did not care about her son and were glad he was leaving.

In the course of our one-on-one interview, Participant 2, Roshawn, spoke of a colleague who helped her secure her son's IEP. She also sought assistance from a local non-profit agency called ASK Family Services. An ASK advocate attended her son's first IEP meeting to provide moral support. During the follow-up interview, Roshawn expressed she and Cairo's IEP coordinator, Ms. Stevens, who also serves 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.

Participant 3's situation is different from the previous two participants. Latrice's son, Justin, no longer has an active 504 Plan. But there are individuals that she speaks highly of within the KPS district and in the community that helped her and Justin. Mr. Benson is the speech pathologist who worked with Justin when he was enrolled in Head Start. Once Justin

transitioned to elementary school, their sessions continued. Latrice sought other avenues to help Justin with his speech impediment when KPS determined that Justin was no longer eligible to receive services. The after-school coordinator with Communities In Schools of Kalamazoo 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 a non-profit agency called Prevention Works, where he was paid to be a peer educator to younger children. Latrice continues to find opportunities for Justin to speak in small and large group settings to get him more comfortable with speaking in front of people.

Jenee, Participant 4, has been raising her brother Gavin for a year. Gavin was recently diagnosed with diabetes. Jenee has found people who have lent support to her and her brother. The school nurse intervened when other KCHS staff were giving Jenee a hard time about the documentation that she provided to staff to show 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 was clear Gavin truly had diabetes, and while he is 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 is written up with the school's 504 coordinator.

Jenee also spoke very highly of another school staff person at KCHS, Mrs. Young, the Student Responsibility Center (SRC) supervisor. In the past, Mrs. Young was a site coordinator with Communities In Schools of Kalamazoo stationed at KCHS. Gavin used to be one of her CIS caseload students. This school year, Mrs. Young started her new position as the SRC

supervisor and is now a KPS employee at KCHS. 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 just because he is no longer on her

caseload. 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 are on track to graduate high school. They have been able to

form relationships with at least one person at KCHS or in the community. Their children's needs

have been met based on this assistance from the individuals in their social network.

Themes That Surfaced During the Follow-up Interview

During the follow-up interview, Roshawn and Jenee named additional individuals who

supported them and helped their children navigate through the late high school years. Even

though they have managed to create social connections with individuals, everyone working at the

school has not embraced them. The themes that surfaced after the data was analyzed were

parents/guardians do not feel welcomed when they go to KCHS, are not being invited to school

events except for IEP meetings and to deal with discipline issues, dealt with the lack of

cultural/social sensitivity displayed by some KCHS staff, and experienced a lack of follow

through (communication) by some KCHS staff.

Parents/guardians do not feel welcome when they go to KCHS. The children of both

parents/guardians who participated in the follow-up interview had been attending KCHS for the

past three years. In this time, neither of the parents felt welcomed when going to the school, specifically when engaging with the main office staff. Roshawn believed that she often received the "cold shoulder" when she visited KCHS because there is not consistent main office staff. Jenee felt that since she is young, 21-years-old, staff do not take her seriously when she goes to the school to advocate for her brother. It is up to schools to provide an atmosphere where parents/guardians feel welcomed coming into school buildings: ". . . Schools need to establish a welcoming climate and an open-door policy so that any parents who have questions can feel confident about coming to the school for answers" (Pena, 2000, p. 52).

> Roshawn said: Honestly, I would say no. Sometimes the front desk staff is rotating.
> There is not much of a rapport or relationships built. So, I would so no. When I go to the
> front desk, I have to state my case, who I am, what do I want, why am I there. It is really
> kind of cold at the front desk.

> Jenee agreed: I would say no, I don't feel welcomed every time I go to the school.
> I think because I'm young and I'm just my brother's guardian they dismiss me.

No invitations to be involved in their child's education. Roshawn and Jenee both expressed that they would like to be more involved in their children's educational life beyond IEP meetings and contact from school staff regarding behavior. No invitations have been extended to them beyond attending IEP meetings and calls about academic or behavior issues. During the follow-up interview, based on their facial expressions and the disappointment in their voices, I could tell that Roshawn's and Jenee's feelings had been hurt sometimes because they had not been invited to school for events. They want to support their children in the school setting more but they are not given the chance.   Parents/guardians felt like they were excluded from invitations to certain events at the school because their child has a disability and because of their child's past

behavior issues. When parents/guardians are only contacted for incidents of negative behavior and academic issues, disagreements over parent involvement may arise (Pena, 2000). KCHS staff only involve Roshawn and Jenee when they feel necessary and thus far have made no attempts to engage them or their children, which means KCHS are likely to continue to arrange meetings and events without parents'/guardians' opinions instead of consulting them to find out their interests and what they would like to participate in (Barton et al., 2004).

> Roshawn responded: The opportunities that are available are just we have an IEP meeting coming up or maybe he is falling behind in a certain area and we need him to get caught up. So really to help problem solve and navigate through problems is when I am called in. But other than that, it is not like I am contacted about Oh we are having an awareness day and we would like you to come in or we just want you to be included and bring him too, No, there is none of that.

> Jenee agreed: No, not at all!

Cultural/social insensitivity by staff. During the follow-up interview the topic of race did come up. Neither of the participants felt as though they or their children were treated differently because they were African Americans. They did describe incidents of cultural and social insensitivity that KCHS staff have inflicted on them and their children more than once. Even though they have been annoyed by these events, Roshawn and Jenee have continued to participate in their child's life based on the limited offerings KCHS staff has provided to them.

> Roshawn responded: With us, my son is socially underdeveloped. Something socially will start, Cairo takes jokes too far, doesn't understand boundaries, pushes the limit until other students are ticked off, yelling at him. He has this stigma of always starting stuff and being into something. So, I wouldn't even say racially, but behaviorally it is always

Cairo. He is pegged as the troublemaker who doesn't get along with anybody. So, the

minute there is an altercation they look to him, What did you do? It does not matter what

the other person said because he is the main one. He is kind of marked in that way

behaviorally.

Jenee said: My brother has come to me plenty of times saying that he feels judged

by certain people. He told me a comment was made about him selling drugs, something

to that effect just because he had some money. I guess they automatically thought that

about him. He said just because I have money does not mean I'm selling drugs. So, I

talked to him and let him know some people just don't understand. They just don't get it.

Jenee has personally been the victim of cultural insensitivity by KCHS staff on more than

one occasion. She has been raising her two younger brothers for over a year due to the death of

their mother. Jenee has legal guardianship of both of her brothers. When she goes to the school,

main office staff question her as to why she is inquiring about her brother, Gavin. Per Jenee,

"They say, 'Oh why are you here? or 'Oh you are just his sister. Where is his mom?' Things

like that. When they can easily look up and see who I am and why I would be there."

It is insensitive for KCHS staff to continue to ask Jenee where her and Gavin's mother is.

After a year, staff should be aware that their mother is deceased. This distasteful line of

questioning could cause trauma for Jenee. A possible solution to alleviate this situation is a note

labeled as a "critical alert" could be placed in eSchoolPLUS (the district's data management

system). The note could state that Jenee is now Gavin's legal guardian due to the fact their

mother has passed away. This simple action could help resolve any questions that KCHS staff

may have as to why Jenee is at the school representing Gavin and not their mother. In addition,

since there is not always permanent staff stationed in the KCHS main office, staff could read the

note in eSchoolPLUS and discover their mom is deceased. Hopefully, questions about their

mother would stop. The fact that KCHS staff do not know the students and their families that

they serve in their building shows a disconnection between the parties. Gavin has attended

KCHS the whole time he has been in high school, which means he was a student at KCHS when

his mother passed away. It is disheartening to think that he lacked emotional support by KCHS

staff since some staff are not even aware that his mom has passed away and continue to inquire

why his sister comes to the school.

It is also culturally insensitive of KCHS staff to assume Gavin's and Jenee's family unit

consists of the traditional mother and father model. In the African American community,

historically, the family unit consisted more of just a mother and father. As far back as slavery,

the African American family unit has been comprised of extended family and fictive kin in

conjunction with blood-related individuals; Extended family (e.g., aunts, uncles, cousins) and

often fictive kin (i.e., individuals of no blood relation, but referred to as family) often financially

support, live with, and are instrumental in raising African American children (Miller-Cribbs &

Farber, 2008; Spruill, Coleman, Powell-Young, Williams, & Magwood, 2014). Even though

Jenee is Gavin's blood sister, their family unit is still unconventional. She is a young adult

raising two teen-agers. Nevertheless, they are a family unit and KCHS staff should recognize

them as such.

Another reason I chose the EPE framework to anchor my study is because it is

constructed partly under the cultural-history activity theory (Barton et al., 2004). Applying this

specific framework to the data collected from my research participants was significant. When

individuals from different cultural and social backgrounds interact with each other in settings

such as schools misunderstandings may occur. The lack of cultural awareness from KCHS staff

towards individuals who are different from them was evident and supported by my research participants' experiences and responses to my questions.

Lack of follow through with communicating with parents/guardians. Another theme that both Roshawn and Jenee spoke passionately about was the lack of follow through by some KCHS staff. Staff actions caused the parent/guardian to feel as though their concerns were not validated by staff. After contacting the special education teacher several times, Roshawn went to the school to get answers directly from her. In Jenee's case, she wanted to accompany her brother to his classes to make sure that he stayed at school. She was told that she needed to get permission from the principal and left her information for the principal to contact her for a meeting. She never heard back from the principal. In fact, she is not even sure if the principal was even given her contact information.

> Roshawn responded: There have been so many, I am going to pass (laughing). Well I
> know there is really no comparison. I have six kids and staff members have 30 kids and
> they are overwhelmed. But sometimes the follow through. You are never waiting on me
> to do anything, but like I said, I don't have 30 kids either. So, I sent an e-mail to the
> Special Education Teacher. It was when Cairo first got to KCHS and I was waiting to
> hear back about the status of his IEP. It was like pulling teeth to get answers. I was like I
> tried four different times and finally I went down to the school like Hi, I'm Roshawn
> Campbell. Remember me? I'm the person who sent you the four emails which are still
> in your inbox. Yeah that's me (laughing). It felt like just getting that ball rolling was
> difficult. The teachers were waiting on that answer. They didn't know what to do
> because they were waiting on her. We couldn't go to point two because we are all
> waiting on one person. It was just kind of frustrating. I know this is not on your radar.

But we need to get this going. We are talking about I gave her over a month and a half to

respond to me. I was also calling every week and the fourth time I just went down there.

It was Oh yeah, we have no problem doing it. It was just the matter of doing it. So that

follow through was just a little frustrating.

      Jenee replied: There is one incident that comes to mind. It was around the time

Gavin was missing school. It got to the point I was bringing him to school, but he would

leave. So, I said, I got something for him today. So, I came up to the school and I said is

there a way I can sit in the classroom with him so I can make sure that he stays? The

secretary said oh no we don't do that; you can't sit in class with him. So, I said, I kind of

feel like my back is up against the wall because I am bringing him to school, but he is

leaving. I felt like the only way I could make sure he was there at the school was to

follow him to make sure that he stayed. So, she told me to write my name and number

down and she would give my information to the principal. I would have to meet with the

principal first because it was a safety concern. I never got a call from the principal. I

don't even think my name and information even made it to the principal. I called to

check up on the situation because I really wanted to come to the school with him to make

sure he was doing what he was supposed to, but nothing ever become of it.

Even though social capital has been formed with some people at the school, Roshawn and Jenee

were not able to leverage their social connections to get responses back when they needed them.

Suggestions from Parents/Guardians to KPS and KCHS Staff

During the follow-up interview, Participant 2, Roshawn, provided suggestions for KPS

and KCHS that she hopes in the future will be implemented.   She suggested creating positions at

the elementary and secondary levels to provide support to parents/guardians raising children with

disabilities and hosting parent orientation/information nights at the beginning of the school year.

These events would be intended for parents/guardians to get know the individuals who will be

working with their children during the upcoming school year and provide training for regular

education teachers because they still have interactions with children with disabilities. Participant

4, Jenee, was in strong agreement with Roshawn's suggestions.

      Create elementary and secondary liaison positions. Roshawn suggested that the

district add two new staff positions, an elementary and secondary liaison. She envisions that the

liaisons would be available for questions about the IEP and 504 Plan process and serve as

advocates for parents raising children with disabilities. Roshawn stressed the importance of these

positions not being held by teachers because they already have so many other tasks and

responsibilities. For instance, during the follow-up interview, Roshawn was not aware that Ms.

Stevens, her son's IEP coordinator, also serves as the KCHS special education department head

and team teaches in other classrooms.

> Roshawn said: A lot of parents have been dealing with this from day one like myself,
>
> (raising a child with a disability). But for instance, if you are starting with the IEP
>
> process, or the 504 Plan process, anything with navigating students with disabilities, there
>
> should be an active liaison at the school to help parents navigate through this process.
>
> And I don't mean a teacher that also helps with this. I mean a person that is dedicated to
>
> this. There is so much stuff you don't know. It would be a good idea to have a liaison
>
> one person for the elementary schools and one person for the secondary schools. You
>
> don't know that when you write your letter to the principal, they have 30 days to respond.
>
> If they don't respond within 30 days, they are held accountable to the next step of action.
>
> But you don't know these things as a new advocate for your child with disabilities.

Host parents' orientation for parents/guardians. Roshawn suggested KPS host a parents' orientation/information night for parents and guardians raising children with disabilities. Similar to events that already occur at the beginning of the school year such as 9th grade orientation. Roshawn believes that hosting an event like this would allow parents and guardians to get know specific individuals who will be working with their children in a more informal setting. Parents and guardians could also meet the individuals they need to contact if any issues arise during the school year or if they have any questions that need to be answered. Planning this type of event would take time but would be worth the effort for the advancement of the child's education and allow for parents and guardians and school staff to start communicating early in the school year (Chavkin, 1989). Roshawn described the benefits to having an orientation/information night for parents/guardians raising children with disabilities at the beginning of the school year:

> If your child has an IEP or a 504 Plan it automatically says your child has a disability and that's what it is. So, helping us through the process is needed. Just like 9th grade orientation, there needs to be an orientation for us. At the beginning of the year each year it would be nice to know who to contact. It would make the rest of the school year better. There needs to be an orientation at the beginning of the year for parents with children with IEPs and 504 Plans, so we know who our advocate is. We are not calling at the beginning of the school year. Counselors can also be present. At the beginning of the school year is so much hustle and bustle; everyone is trying to get their schedules changed, no one is trying to do all this. Help us navigate this and not have to wait until the middle of the school year and say oh you are the one I was supposed to talk too. We will know ahead of time.

The parent orientation/information night is a prime example of an activity that school districts receiving Title I could conduct in order to foster parent involvement and engagement. This event would allow parents/guardians to meet school staff in a more relaxed setting. In addition, parents/guardians and school staff would begin to get to know each other early in the school year in order to start developing collaborative relationships.

Training for regular education teachers. Even if a student is receiving special education services, there are often certain classes in their schedule where they may be mainstreamed (in a class being taught by a regular education teacher). Some regular education teachers have voiced their own concerns about not being trained to work with students with disabilities. Biklen (1985) wrote, "regular educators have not been trained and are, therefore, not prepared to integrate disabled youngsters into their classrooms" (p. 59). Providing some type of training to regular education teachers may be helpful to them and provide some ease with teaching children with disabilities. During the follow-up interview, the topic of training for regular education teachers working with children with disabilities surfaced.

> Roshawn replied: Regular education teachers aren't trained to deal with students with disabilities in conjunction with their already full classes. It's like the dog that barks the loudest, so whoever is drawing that attention. They are putting out fires all day. Any training to equip this group with what they need, because they are too busy trying to keep the class quiet. So, with that lack of training in conjunction with the burn out, I'm tired, because I don't know how to really do it all. It's a lot and our kids feel the brunt of it.

Based on her experience with raising a child with a disability, Roshawn expressed her concern for the absence of training to regular education teachers. In her opinion, regular education teachers are not prepared to work with children with disabilities. From Roshawn's perspective

their lack of training in the area of teaching children with disabilities may lead to teacher burn out.

Suggestions from Researcher to KCHS and KPS Leadership

During the follow-up interview, certain themes came forth concerning raising children with invisible disabilities attending KCHS within the KPS district. It is my sincere hope that KCHS and other KPS staff reflect on how their treatment of parents/guardians and children with invisible disabilities have had negative effects. I hope that staff consider these suggestions as a starting point in developing relationships with parents/guardians and children with invisible disabilities. Based on those themes that surfaced from the data, please see my suggestions below.

Create an environment to make parents/guardians feel welcome. When you go into any business, the individuals in the main office set the tone and influence whether you would like to come back and engage again at that business. A school building is no different. It may be disheartening for some individuals to keep coming to a place where they do not feel welcomed while their child is going to school there. If parents/guardians did not feel welcome stepping into the main office, they were not going to feel welcome interacting with teachers or participating in school activities. It is the school's responsibility to foster an environment that is welcoming along with an open-door policy so parents/guardians who have questions that need to be addressed feel positive about going to the school for solutions (Pena, 2000). School staff can make the school setting a more welcoming place and invite families into the building for an array of events and activities (Baker et al., 2016; Hoover-Dempsey et al., 2005). Invitations to participate in school activities create a school environment that shows parents that school staff value their presence and desire to help their children succeed academically (Bardroff-Zieger & Tan, 2012). These

invitations can possibly foster school staff learning about parents' goals for the child, allow for the school staff to gain knowledge of the family structure, and start a dialogue which could conceivably create open communication between school staff and parents (Hoover-Dempsey et al., 2005). School staff interacting with parents on an intimate level may also inspire them to make parent involvement a regular part of their planning and shift their thinking away from the notion that parents are out to get them (Hoover-Dempsey et al., 2005).

Invite parents/guardians to the school. Roshawn and Jenee both reflected in the follow-up interview that they would like to be even more active in their child's educational life and support the school as well. But they do not receive invitations to come to the school unless it is for an IEP meeting or there is an issue pertaining to the child. School staff assume that parents/guardians have little interest in supporting their children's educational interests: "Parents wanted to support the school by going to school performances, by helping their children at home, and by assisting in school events" (Chavkin, 1989, p. 120). KCHS has not tapped the potential of these parents and the relationships that could be built. They have parents willing and able to participant in school events and activities that have not been extended an invitation.

Respond to parent/guardian correspondence in a timely fashion. During the follow-up interview, the participants described incidences where KCHS staff lacked follow through and did not get back in communication with them regarding situations with their children. Roshawn e-mailed the special education teacher several times within a month about a situation. The special education teacher never responded to the e-mails so Roshawn decided to go to the school and get an answer from the teacher in person. Jenee's brother started skipping school after he was diagnosed with diabetes. She wanted to know if she could escort her brother to his classes to make sure that he stayed at school. She was told that she would have to discuss being in the

building for an extended amount of time with the principal. The principal never contacted Jenee to discuss if she would be able to escort her brother to his classes. Jenee does not believe that her message even made it to the principal.

      Cultural/social training for all staff. KPS is an urban school district with close to 13,000 students. Due to the mixture of students who are enrolled in the district, it is important for the staff who necessarily do not come from the same cultural and social backgrounds as the students to receive cultural/social training on a regular basis. It would be difficult to engage with students and their families if you are not aware of their cultural/social traditions. It would be helpful to school staff, including teachers, to be open to receiving training on how to interact with students and their families from different cultural/social backgrounds. Based on comments and actions towards Cairo and Gavin, KCHS staff have showed cultural and social stereotypes towards African American students. Roshawn's son is portrayed as the troublemaker anytime a situation occurs in class. Jenee's brother, Gavin, was asked by KCHS staff if he sold drugs on more than one occasion just because he had money at school. Staff at KCHS also do not realize the trauma that they could possibly cause to Jenee when she comes to the school. She is often confronted with questions as to where their mother is. After a year, individuals should be aware their mother is dead and Jenee is now Gavin's legal guardian. Some KCHS staff are not in tune with what is occurring in the lives of their students and their families even tragic events such as a death of a parent.   Also, the assumption that all families consistent of a mother and father is a cultural bias. Examples presented by Roshawn and Jenee are illustrations of KCHS staff biases projected on individuals who come from different cultural/social backgrounds.

      KPS may want to become familiar with the work done by Maya Kalyanpur and Beth Harry (1997). Both scholars are viewed as experts in the field of special education. Harry was

also a parent of a child with a disability. The duo developed a system called the Posture of

Reciprocity, which is geared towards providing professionals working with parents/guardians

raising children with disabilities tools to foster positive relationships with individuals from

different backgrounds. Posture of Reciprocity "enables professionals to develop collaborative

relationships with families from culturally diverse backgrounds by becoming aware of

assumptions underlying both their and the families' responses to the child with disabilities"

(Kalyanpur & Harry, 1997, p. 489). Without intervention, misunderstandings between parents

and professionals are bound to continue. Conflicts between parents/guardians and professionals

seldom improve when the parties come from different cultural backgrounds (Kalyanpur & Harry,

1997). Valuing individuals from different social and cultural backgrounds is essential to

avoiding the misplaced stereotypes that KCHS staff projected onto their students as described

earlier by Roshawn and Jenee (Harry, Rueda, & Kalyanpur, 1999). There are four steps to

Posture of Reciprocity:

1. Identify the cultural values imbedded in the professional interpretation of a student's
   difficulties or in the recommendation for service.

2. Find out whether the family being served recognizes and values these assumptions
   and, if not, how their view differs from that of the professional.

3. Acknowledge and give explicit respect to any cultural differences identified, and fully
   explain the cultural basis of the professional assumptions.

4. Through discussion and collaboration set about determining the most effective way of
   adapting professional interpretations or recommendations to the value system of the
   family (Kalyanpur & Harry, 1997, p. 498).

KCHS and the KPS district may want to evaluate the interactions that their staff have with the children and parents. Part of the behavior that children and parents display may be due to the treatment that they have received from their staff. They have offended individuals without possibly even being aware they have done so.

Develop a graduation tracking system. A system needs to be devised where students meet annually with their guidance counselor to select their classes for the following year. At that time, students are made aware of whether they are on track to graduate within four years. Based on my research (data collected from Marie, Participant 1, on her son's account of his interaction with his guidance counselor), a policy change within the KPS district needs to be enacted where a student's credits are audited on an annual basis. Conducting an annual audit of credits is pertinent for all students, not just children with invisible disabilities. If the student has fallen below the benchmark to move on to the next grade, this situation should be communicated to the parent/guardian immediately. A meeting needs to be conducted between the parent/guardian, the child and the guidance counselor in person or via telephone. During the meeting, a plan of action needs to be devised between the parent/guardian, the child, and the guidance counselor (i.e., can the child attend summer school to make up the credits, or would it be best for the child to transfer to the alternative school within with the district).

It is an extreme case, but Marie, was not notified by KCHS staff that her son Nick was classified as a senior, but only had earned the credits of a 10th grader. Nick was only informed that he was not going to graduate this year because he made an appointment to speak to his guidance counselor regarding another issue. He was given the option to stay at KCHS for the remainder of this school year and then transfer to the alternative high school which does not offer special education services. News of that magnitude should not have just been a surprise to Nick

or Marie. Both Nick and Marie should have been fully aware that there was no way possible for

him to graduate this year with his class. It is my hope that a policy change of an annual auditing

system for students will ensure that all students and parents/guardians are aware graduation

requirements.

Suggestions from Researcher to Parents/Guardians

The section below contains suggestions that based on the data that was gathered, I felt

would be of assistance to parents/guardians raising children with invisible disabilities. These

suggestions could possibly help parents/guardians construct their social networks. Having a

social network is critical to ensuring your child's needs are met.

A good way to develop your social network is to start first with communicating with your

child's teachers and other staff that interact with your child. Some school staff will be more

receptive than others to building relationships with parents/guardians. If one person does not

want to partner with you, think of other avenues to get your questions answered and your child's

needs met.

Another way to build your social network is locate advocates that can assist you in

learning how to navigate the K-12 system. In the Kalamazoo area, there are non-profit agencies

that assistant parents/guardians raising children with all disabilities, not just invisible disabilities.

ASK Family Services (formally known as Advocacy Services for Kids), The Arc Community

Advocates, and Disability Network are all organizations that provide free services such as

advocates who will attend IEP and 504 meetings, are knowledgeable about special education

laws, and offer support groups that focus on various topics that pertain to parents/guardians

raising children with disabilities. Communities In Schools of Kalamazoo (CIS) is a non-profit

agency that partners with KPS. CIS staff are stationed in 20 of the 26 schools that comprise the

KPS district. CIS offers daytime site coordinators who ensure services are provided to students during the school day (i.e., medical, dental, vision, food pantries, mental health, and academics) and after school programs that are considered extensions of the school day. Students are provided homework assistance, enrichment activities and dinner four days a week during the school year. "Indeed, the onus is on parents to identify the types of available options and become informed about the appropriateness of these various programs for their child with disabilities in order to determine which would be most suited to their child's needs" (Kalyanpur, Harry, & Skrtic, 2010, p. 129). Please see the quote below from Roshawn. She described how she sought support from a community agency:

> When I started this process, I went to ASK (Advocacy Services for Kids). I went to the agency and there is an advocate that will come with you to the IEP meeting and will teach you everything about the process, help you navigate, help push the buttons that need to be pushed. So, once she taught me how to do it, I was like I got this, you can go back to your office, I got it from here. I have been doing it for the last 16 years, but what about the parents that are new to the process, a year or two in. It can be an overwhelming.

Developing relationships with a teacher, or someone who works for an agency outside of the school is essential to getting your child's needs met and ensuring they are progressing academically. Based on my research, participants' experiences, having a social network (relationships) with individuals in the school or with someone in the community made the difference between a child with an invisible disability graduating on time or not. Even if you cannot find someone at KCHS, as mentioned before, there are non-profit agencies in the area that are willing and able to assist you for free. Get informed and be involved.

Further Research

In the limitations section, I acknowledged having a small sample size (four participants) of which only two attended the follow-up interview limited my study. A possible strategy to mitigate this issue would be implementing a longer time frame to recruit a larger number of participants. Additional recruitment time would allow me to be more selective about the individuals that participate. In addition, with a larger pool of participants that will be recruited, a diverse sample of participants may be obtained. I am interested in exploring the experiences of parents/guardians navigating children with invisible disabilities from different races and ethnic backgrounds. With a larger sample size, I am hopeful that I will be able to attract parents/guardians who are single fathers, grandparents, foster parents, aunts, uncles, and even fictive kin to the child with an invisible disability. It is my desire to conduct a focus group with my participants in my next study. I believe that a focus group will add another dimension of securing information. Conversations can be had with participants about social capital regarding the perspectives of their own social capital and how they attained it. Gathering data in a group setting with a larger sample size will add validity, reliability, and generalizability to my future study. With the data that I gather having a larger sample size and conducting a focus group, my data will inform future research because it will be more illustrative of the diverse individuals whose children attend KCHS within the KPS district. In addition, reporting the experiences of single fathers, grandparents, and individuals who are not biologically related to the child is more representative of the ever-changing reality of what family units are.

An additional topic that should be researched is the number of students with invisible disabilities taking advantage of the Kalamazoo Promise. When I was trying to locate the number of students with 504 Plans (students mainly with invisible disabilities) that were in the KPS

district, I discovered that the information is not available on the State of Michigan (MI School

Data website). Only the number of students who have IEPs in the district. It would be useful to

learn how many students from the KPS district who have IEPs and 504 Plans are taking

advantage of the Kalamazoo Promise and track their performance in college and to see if they are

receiving services through their college/university's disability offices.

Chapter Summary

In this chapter, the themes that surfaced from the participants during the semi-structured

one-on-one interviews and the follow-up interview were discussed in greater detail.   In addition,

suggestions from research participants and me to KCHS and KPS were presented. The EPE

framework guided this study. The various components of the conceptual framework (i.e., focus

on urban elementary school, culture awareness, parent engagement/involvement, and capital,

particularly social capital) were the reason the framework was chosen. The work of Pierre

Bourdieu was highlighted because of his expertise on capital, namely social capital within

educational systems among marginalized populations. The major theme that was uncovered after

the one-on-one interviews was social capital. The one participant who did not have social

relationships with KCHS staff or individuals in the community unfortunately found out that her

son is not going to be able to graduate this school year. Social capital is an essential resource for

parents raising children with invisible disabilities to possess in order to ensure that the child's

needs are met.

Even with the social connections that have been built, discouraging themes were

expressed by the participants who participated in the follow-up interview. They cited feeling

unwelcomed when they walk through the doors of KCHS, not being invited to school except for

IEP meetings or discipline issues, that they experienced cultural/social insensitivity and dealt

with the absence of follow through by some KCHS staff. Even with feeling slighted, Roshawn and Jenee continue to be involved and want to be involved beyond the occasional calls to schedule IEP meetings and in relation to their child's behavior. Cultural biases that KCHS staff have leveraged against Jenee were discussed: Staff questioning Jenee about her mother when she goes to the school and not acknowledging that her family unit does not consist of a mother and father.

The following suggestions were offered by the participants to KPS and KCHS staff: KPS may want to investigate employing elementary and secondary liaisons, host orientations for parents/guardians raising children with disabilities, and train regular education teachers to work more effectively and respectfully with children with disabilities. The participants felt as though their suggestions would start the development of more effective relationships between parents/children and school staff.

The suggestions that I would like KPS/KCHS leadership to consider are the following: create an atmosphere where parents/guardians feel welcomed when entering the school doors, invite parents/guardians to the school for more than IEP meetings and behavior concerns, work on following through with communication with parents/guardians, complete cultural/social training modeled after the work conducted by Maya Kalyanpur and Beth Harry, and develop a system where parents/guardians and child are notified if the child is not on track to graduate. I believe the suggestions that I provided to KPS/KCHS may start conversations for the parents/guardians and school staff to help begin building collaborative relationships. My suggestions to parents/guardians are to form their social networks with school staff or with individuals from local non-profit agencies. It is up to the parents/guardians to locate programs and services that meet their child's needs. Also, do not get discouraged if someone at the

school does not want to partner with you and be a part of your social network. Other staff may

want to assist you, or you can secure an advocate through a local non-profit agency. The

creation of relationships between parents/guardians and school staff is important in order to

make sure that the child's needs are met. Lightfoot (1981) compared parents, children, and

school staff relationships to a triangle. There are three viewpoints, but the most important

viewpoint should be the child's. When adults remember the reason why they are interacting

with each other (because of the child), only then can the best interest of the child be

accomplished, and the child's needs met.

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APPENDICES

Appendix A: Human Subjects Approval Letter

Nov 16, 2018 9:06 AM EST

Tamiko Garrett
Eastern Michigan University, Leadership and Counsel

Re: Expedited Review Initial UHSRC-FY18-19-95 Case Study of Parents' Experiences as Their Children with Hidden Disabilities Navigate the K-12 System to High School Completion

Dear Tamiko Garrett:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for Case Study of Parents' Experiences as Their Children with Hidden Disabilities Navigate the K-12 System to High School Completion. You are approved to conduct your research.

Decision: Approved

Selected Category: 7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Findings: You must use stamped copies of your recruitment and consent forms.

To access your stamped documents, follow these steps; 1, Open up the Dashboard; 2. Scroll down to the Approved Studies box; 3. Click on your study ID link; 4. Click on "Attachments" in the bottom box next to "Key Contacts"; 5. Click on the three dots next to the attachment filename; 6. Select Download.

Renewals: This approval is valid for one year and expires on November 15, 2019. If you plan to continue your study beyond November 15, 2019, you must submit a continuing review application in Cayuse IRB at least 14 days prior to November 15, 2019 so that your approval does not lapse.

Modifications: All changes to this study must be approved prior to implementation. If you plan to make any changes, submit a modification request application in Cayuse IRB for review and approval. You may not implement your changes until you receive a modification approval letter.

Problems: All deviations from the approved protocol, unanticipated problems, adverse events, subject complaints, or other problems that may affect risk to human subjects or alter their willingness to participate must be reported to the UHSRC. Complete the incident report application in Cayuse IRB.

Please contact human.subjects@emich.edu with any questions or concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee

Appendix B: Recruitment Flyer

Case Study of Parents' Experiences as Their Children with Invisible Disabilities Navigate the K-12 System to High School Completion.

This study is Affiliated with Eastern Michigan University

REQUEST FOR RESEARCH PARTICIPANTS

Who is conducting the study and what is this study about?
Researchers from the Leadership & Counseling department at Eastern Michigan University are recruiting participants for a study to learn more about the experiences of parents navigating their children with invisible disabilities from high school to graduation.

Why should I join this study?
Participation in this study will possibly help to shape the way that parents learn and receive information about the services that their children may be eligible to obtain.

Who can join this study?
1. Be a parent/guardian of a child with a diagnosed invisible disability
2. Child must be in the 11th or 12th grade
3. Child must attend Kalamazoo Central High School

How do I join this study?
If you want to join this study, contact the Co-Investigator or the Principal
Investigator utilizing the contact information listed below.

What will I be asked to do?
1. Participate in a one-on-one semi-structured interview (45-90 minutes)
2. Participate in a focus group (45-90 minutes)

PLEASE CONTACT US FOR MORE INFORMATION	
Tamiko L. Garrett (Principal Investigator) **269-599-3381** **tgarret7@emich.edu**	**Dr. Rema Reynolds (Faculty Advisor)** **Assistant Professor, Department of Leadership &** **Counseling** **Eastern Michigan University** **rreyno15@emich.edu**

Appendix C: Informed Consent Form

RESEARCH @ EMU

Informed Consent Form

Project Title: Case Study of Parents' Experiences as Their Children with Hidden Disabilities Navigate the K-12 System to High School Completion

Principal Investigator: Tamiko Garrett, Doctoral Student, Eastern Michigan University

Faculty Advisor: Dr. Rema Reynolds, Eastern Michigan University

Invitation to participate in research

You are invited to participate in a research study. In order to participate, you must a parent/guardian of a child with an invisible disability, the child must be in the 11th or 12th grade and the child must currently be enrolled at Kalamazoo Central High School (KCHS) a traditional high school in the Kalamazoo Public School (KPS) district to be considered for participation. Participation in research is voluntary. Please ask any questions you have about participation in this study.

Important information about this study

- The purpose of the study is to examine the experiences parents are having or not having in the KPS district as they navigate their children with hidden disabilities through the K-12 system.
- Participation in this study involves a 3-step process 1) an individual in-person semi-structured interview. The estimated timeframe for the interviews will be 45-90 minutes. 2) A member check; participant's will be provided a copy of their interview transcript in which they will have the opportunity to read and determine if the researcher interpreted their answers to my questions correctly from their semi-structured interview. 3)   A focus group interview will be conducted with all the participants. This will be an opportunity for participants to interact with each other and for the investigator to gather additional data to be utilized in the study.
- Risks of this study are minimal. Individuals will only know that a participant is a part of the study if they disclose the information.
- The investigator will protect your confidentiality by securing data collected in a locked cabinet that only researcher will have access too. All the names of participants will be masked by pseudonyms to protect identities.
- Participation in this research is voluntary. You do not have to participate, and if you decide to participate, you can stop at any time.

What is this study about?

- The purpose of the study is to examine the experiences parents are having in the KPS district specifically at Kalamazoo Central as they navigate their children with hidden disabilities through the K-12 system. The investigator will conduct a case study with 4-6 participants. Through the case study, the investigator seeks to discover the experiences and supports/services that are and are not available to parents in the KPS district. It is a hope that the findings of this case study will provide insight on how parents would like to receive information, supports, and resources from KPS district staff, in addition to what parents may feel is lacking in their experiences with KPS district.

What will happen if I participate in this study?

Participation in this study involves
- 1) Semi-Structured individual interview, 2) member check, and 3) Focus group interview.
- Visit 1: A semi-structured individual one on one interview will be conducted with all participants. Visit 2: Member check; Participants will be asked to read their responses from their semi-structured interview to verify that the investigator captured their responses correctly. This visit can be done in person or via e-mail. Visit 3: Focus group interview. All participants will be asked to participant in a focus group interview. Participants will be asked a series of questions and interact with each other in a hope that additional information will be gathered for the investigator to utilize.
- Visit 1: the estimated time for the semi-structured interviews is 45-90 minutes; Visit 2: the estimated time for the member check is 20-30 minutes; Visit 3: the estimated time for the focus group interview is 60-90 minutes.

We would like to audio record you for this study. If you are audio recorded, it will be possible to identify you through your voice. If you do not agree to be audio recorded, you may not be eligible to participate in this study.

What types of data will be collected?

We will collect data about the experiences of parents who are navigating children with invisible disabilities through KCHS a high school in the KPS Kalamazoo district.

What are the expected risks for participation?

There are no expected physical or psychological risks to participation.

The primary risk of participation in this study is a potential loss of confidentiality.

Some of the semi-structured interview and/or focus group interview questions are personal and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. If you are upset, please inform the investigator immediately.

Are there any benefits to participating?

You will not directly benefit from participating in this research.

Benefits to society include contributing to the discussion of parents navigating children with invisible disabilities within K-12 educational system.

How will my information be kept confidential?

We plan to publish the results of this study. We will not publish any information that can identify you.

We will keep your information confidential by masking all the names of participants by pseudonyms to protect identities. This will be done to ensure that no retaliation will be taken against the parents/caregivers or their children since they live in the community and the children attend KCHS a high school in the KPS district. Your information will be stored in a locked filing cabinet that only the investigator will have access too.   We will store your information for at least three years after this project ends, but we may store your information indefinitely.

We will make every effort to keep your information confidential, however, we cannot guarantee confidentiality. The principal investigator and the research team will have access to the information you provide for research purposes only. Other groups may have access to your research information for quality control or safety purposes. These groups include the University Human Subjects Review Committee, the Office of Research Development, the sponsor of the research, or federal and state agencies that oversee the review of research, including the Office for Human Research Protections and the Food and Drug Administration. The University Human Subjects Review Committee reviews research for the safety and protection of people who participate in research studies.

If, during your participation in this study, we have reason to believe that elder abuse or child abuse is occurring, or if we have reason to believe that you are at risk for being suicidal or otherwise harming yourself or others, we must report this to authorities as required by law. We will make every effort to keep your research information confidential. However, it may be required by law that we must release your research information. If this were to occur, we would not be able to protect your confidentiality.

The investigators will ask you and the other people in the group to use only first names during the focus group interview session. The investigators will also ask you not to tell anyone outside of the group about anything that was said during the group session. However, we cannot guarantee that everyone will keep the discussions private.

Storing study information for future use

We will store your information to study in the future. Your information will be labeled with a code and not your name. Your information will be stored in a password-protected or locked file and will be stored indefinitely.

We may share your information with other researchers without asking for your permission, but the shared information will never contain information that could identify you.

What are the alternatives to participation?

The alternative is not to participate in this study.

Are there any costs to participation?

Participation will not cost you anything.

Will I be paid for participation?

You will not be paid to participate in this research study.

Study contact information

If you have any questions about the research, you can contact the Principal Investigator, Tamiko Garrett, at tgarret7@emich.edu or by phone at 269-599-3381. You can also contact, Dr. Rema Reynolds, at rreyno15@emich.edu or by phone at 734-487-2713.

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734-487-3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, without repercussion. You may choose to leave the study at any time without repercussion. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

Statement of Consent
I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

_____
Name of Subject

_____   _____
Signature of Subject   Date

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

_____
Name of Person Obtaining Consent

_____   _____
Signature of Person Obtaining Consent   Date

Appendix D: Semi-Structured Interview Questions

1. Which high school does your child attend?

2. What grade is your child in?

3. How long has your child been enrolled at KPS?

4. At what age was your child diagnosed with their invisible disability?

5. What is your child's invisible disability?

6. Describe the event when you realized there was an issue with your child?

7. Who initiated the process to have your child diagnosed with the invisible disability?

8. Does your child have a 504 Plan or an IEP?

9. Would you mind providing me a copy of your child's 504 Plan or IEP? (I would like to look at accommodations and services your child is supposed to be receiving).

10. Describe the process of securing your child's 504 Plan or IEP?

11. Is your child's 504 Plan or IEP reviewed on a regular basis?

12. Do school staff follow the accommodation/services outlines in your child's 504 Plan or IEP?

Appendix E: Follow-Up Questions

1. Do you feel welcome by staff when you go to KCHS?
2. How do you define or describe parental involvement?
3. Do KCHS staff include you in situations involving your child? How?
4. Do KCHS staff provide you with opportunities to be involved in school activities? How?
5. Do you feel like you are an involved parent? How? What activities do you participate in?
6. Do you see a difference in involvement opportunities from when your child was in elementary versus high school?

7. How do you find out about school activities/events?
8. What role do you feel like KCHS Administration pay in parental involvement?
9. Have you ever had any cultural/social/or racial issues with KCHS staff that may have influenced your parent involvement/engagement in the school? How? If so in what ways?
10. Do you feel like KCHS staff is preparing your child to take advantage of the Kalamazoo Promise?
11. What types of services/accommodations have been provided to you by KCHS staff during your child's late high school years to high school graduation?
12. Which services/accommodations by KCHS staff helped your child's during their late high school years to high school graduation?
13. Reflect on an instance when a KCHS staff person helped you during your child's late high school years. Describe what they did or said.
14. Reflect on an instance when a KCHS staff person hindered you during your child's late high school years. Describe what they did or said.
15. Any closing thoughts on parental involvement and your experience at KCHS?