The Relationship Among Children Born with a Congenital Heart Defect, Effects of General Anesthesia, and Special Academic Needs

Lorilynn Bowie

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The Relationship Among Children Born with a Congenital Heart Defect, Effects of General Anesthesia, and Special Academic Needs

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The Relationship Among Children Born with a Congenital Heart Defect, Effects of General Anesthesia, and Special Academic Needs

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of the Requirements of
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Abstract

I initiated this study due to experience in the public education system in one state in the United States. I noted a lack of understanding among educators on how to meet the educational needs of children born with a congenital heart defect (CHD) who had undergone general anesthesia related to their CHD. A lack of communication between the medical sector and the educational world led to extensive delays in children receiving the educational support they needed to be successful academically. There were two primary exploratory questions that drove my study: 1.) Is there a relationship between children born with CHD and their being determined eligible for a program under the Individuals with Disabilities in Education Act (IDEA) criteria? 2.) Is there a relationship between how long a child has been under general anesthesia and his or her being determined eligible for a program under IDEA criteria? Through my study, I concluded there is a relationship among children born with CHD, exposure to general anesthesia, and being determined eligible for a program under the IDEA criteria. I recommend that hospitals with a Pediatric Cardiology Specialty Department implement an Administrative Educational/Medical Professional position to assist families as early as possible in meeting not only the medical needs but also the academic needs in their child’s life.
Preface

May 4, 1991, a day that I will remember as though it were yesterday. I am midway through my pregnancy with my son. It is just after dinner time when I receive a call from my dad, “Mom just passed out on the floor; what do I do?” I tell my dad to call 911 and I will meet him at the emergency room. Mom worked for the ex-mayor as a paralegal. I talked to her an hour earlier; she was tired but fine.

Here we are, in the emergency room. Mom is in a room; we are waiting to hear from the doctor. Dad is panicking; Mom is our family rock. The doctor comes in and says he thinks it is just angina, but to be safe, he wants to do a heart catheterization. We all go up the elevator together. Mom is talking and apologizing for scaring us. We separate and they take Mom to the operating room for the procedure.

It is now approximately 11:00 p.m. The doctor comes and gets my dad and me. He tells us we have to see this to believe it and takes us to a dark room with a computer monitor. On the monitor is Mom’s heart, not beating except for the lower left quadrant; the rest of her heart is “dead.” The doctor tells us she is not a transplant candidate and that our best hope is that she pass peacefully and quickly, not on life support. I do not remember a lot for the next hour.

It is now approximately 2:00 a.m. They move Mom to a room. Mom has a Do Not Resuscitate (DNR) and is hooked up to machines, so we can say ourgoodbyes. Dad and I go in. Mom is not lucid; we are crying and trying to understand what is happening. Mom stops breathing, alarms go off, and we are ushered out of the room. Fifteen minutes later, Mom is pronounced dead. This is the night that changed me in so many ways.

The next year was nothing less than surreal. My dad had a “bad heart” as they
used to say. I spent the next year going to every cardiologist and pulmonologist I could imagine. The consensus was, “your dad is on borrowed time.” His heart was diseased from years as a blue-collar worker, and it was enlarged to where you could actually watch it beating in his chest. Seventeen months after Mom died, Dad died peacefully at home.

My passion has always been educating children with special needs. There is a different kind of need, love, desire, and motivation these children possess. As an adult with learning disabilities who hated school, I make it a priority to help children with special needs to not hate school. In my more than 30 years as an educator, I can say with 100% certainty, unseen disabilities are the number one cause of high school dropout.

How do the children with Congenital Heart Defects (CHD) fit into this? As my disabilities are not able to be visible, neither are theirs. I became involved with the American Heart Association Heart Heroes (AHAHH) 18 years ago. I started as an educator helping parents understand their children’s needs as they related to learning before, during, and after surgeries. I learned very quickly this was a very novel thought which was welcomed with open arms. Working with pediatric cardiologists and discussing anesthesia and the lingering affects prompted me to do this study.
Dedication

This work is dedicated to my family: Bill, Shannon, A.J., and Deac for their encouragement, undying support, patience, and love during this journey.

This study is also dedicated to every family, fighting the fight, tirelessly, attempting to advocate for their child with “hidden” disabilities to acquire the help they so desperately need to be successful academically.

I am also dedicating this study to the American Heart Association, Heart Heroes. Thank you to Pepper Adair and Julie Ortiz and their team of dedicated individuals, advocating, educating, and supporting our families of children with Congenital Heart Defects.
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CHAPTER ONE

Introduction

I chose this dissertation topic due to my passion and experiences in helping all children with special needs combined with a family history of heart conditions. I created this study due to the resistance of school psychologists and classroom teachers and school-based administrators to help children with non-visible disabilities. This study was a direct attempt to bring attention to meeting the needs of children struggling to learn. The purpose of this study was to draw awareness with research supported data to validate the diverse learning needs of children born with Congenital Heart Disease (CHD). One of the characteristics of children with CHD is impaired neurodevelopment: “Children with early surgery for congenital heart disease (CHD) are known to have impaired neurodevelopment; their performance on school-age achievement tests and their need for special education remains largely unexplored” (Mulkey et al., 2016). Students who are not able to learn grade level material at the same rate as their peers, are to receive interventions in specific content areas in an attempt to close the educational gap. Interventions may be implemented in small group settings, pairs, or one on one depending on the severity of the deficit. These interventions are to be charted and graphed for effectiveness toward the desired result.

Through my experiences in public education, the children with “unseen” disabilities were often unidentified. If a child had a visible disability, they were immediately assumed to have deficits in learning. This generalization was far from true for many of the students. When the brain has been affected by anesthesia, the child typically, walks, talks, looks, and communicates verbally the same as their peers. The
inability to process information was not “seen”; therefore, the student was often perceived as lazy, defiant, or unwilling to try. Students attempting to do their best, yet constantly struggling or failing, often became behavior concerns as well.

When the struggling student was not identified to receive assistance, they became disengaged. When students became disengaged, they did not grow academically; therefore, they failed. When students continually and continuously failed, they became a statistic and dropped out of school. This was the ultimate travesty we could have prevented through proper identification early in a child’s academic career.

**Rationale**

I chose this dissertation topic due to my passion for helping all children with special needs combined with my family history of heart conditions. I was led to this topic through my love of children and passion for children with special needs. I also created this study due to the resistance of school psychologists and classroom educators and school-based administrators to help children with non-visible disabilities. One of the critical issues embedded in this study is the lack of understanding of the educational community regarding the medically valid reasons for a child to struggle to learn due to the prolonged effects of anesthesia. This study was a direct attempt to bring attention to meeting the needs of children with CHD struggling to learn.

This study was important to me as I have been a member of the American Heart Association Heart Heroes (AHAHH) for the past 18 years and have heard the pain in parents’ voices and have seen the pain in children’s faces. When a child “looks normal” except for the huge scar down the middle of a child’s chest that they do not let anyone see, these children are often viewed as willful, slow, uncooperative, or unable. This
perception is heinous and cruel as these children want to do better; their brains just cannot put it all together. The worst part is, they are smart, they know they are different, they just do not know why. I wanted to give them the answer, the why, so they would know it is not an inability to learn; their learning difficulties have defined them due to their heart history.

This study was imperative to all stakeholders such as the children, parents, educators, and medical professionals to finally have a comprehensive understanding of why and how the child learns. This knowledge will assist them in problem solving on how to help the child. For the children, it will let them know they are able and can do what is being asked of them in the classroom, they may simply need accommodations or modifications to learn. For the parents, the information obtained through this study will allow them a tool to help them advocate for their child and to access the help needed to be successful in school. For the educators, the hope was that they will listen, learn and embrace this information to assist them in meeting the needs of children with CHD. For the medical community, the research will validate for them, needed information they can share with parents to help them better understand potential outcomes and prepare them for potential challenges ahead.

The purpose of this study was to draw awareness with research supported data to validate the diverse learning needs of children born with CHD. Through my experience in the public education community, there has been negativity and resistance to understanding the medical implications for children born with CHD and their learning and behavioral concerns. When a study is able to draw a significant relationship among a
medical condition and learning needs, the educational world listens. It was time for there to be a document to assist all stakeholders understand our diverse children.

**Goals**

My goal was to bridge the gap between the medical world and educational world to understand and embrace our children born with CHD to help them succeed. This was by no means an easy task to take on; however, it was imperative that the two most impactful institutions for a child born with CHD were able to understand each other and communicate clearly to assure the child’s success in school and in life. As I began my research on children who were born with CHD, my desire was to expand my study to include any and all children who had undergone general anesthesia and their need for special education and related services under the Individuals with Disabilities in Education Act (IDEA) criteria.

For my goal to impact student learning, it needed to be disseminated via pediatric cardiologists, medical journals, and educational journals. Whenever possible, face to face presentations of this study would be most impactful. The terminology used had to be basic enough for all to comprehend yet complex enough to have an impact.

**Definition of Terms**

1. **Atrial Septal Defect** is a hole in the wall between the two upper chambers of the heart (atria). (Mayo Clinic, December 20, 2018)

2. **Atrioventricular Defect** occurs when there is a hole between the heart’s chambers and problems with the valves that regulate blood flow in the heart. (Mayo Clinic, July 14, 2018)
3. **Bicuspid aortic valve** is a condition in which the aortic valve located between the lower left heart chamber (left ventricle) and the main artery that leads to the body (aorta) has only two cusps (bicuspid) instead of three. (Mayo Clinic, October 4, 2018)

4. **Coarctation of the Aorta** is the narrowing of the large blood vessels (aorta) that lead from the heart. (Mayo Clinic, March 6, 2018)

5. **Comorbidity** is the coexistence of two or more disease processes. (Brown, & Thorsteinsson, 2020)

6. **Congenital** means it is present from birth. Congenital Heart Defect or Disease is one or more abnormalities in the heart’s structure that a person is born with. (Mayo Clinic, Oct 4, 2018)

7. **Double-outlet right ventricle** is a disease that is present from birth where the aorta connects to the right ventricle (RV, the chamber of the heart that pumps oxygen-poors blood to the lungs) instead of the left ventricle (LV, the chamber that normally pumps oxygen-rich blood to the body). (Mayo Clinic, March 6, 2018)

8. **Hypoplastic Left Heart Syndrome (HLHS)** is where the left side of the heart cannot effectively pump blood to the body. (Mayo Clinic, August 4, 2018)
   Pulmonary Atresia, the valve that lets blood out of the heart to go to a baby’s lungs (pulmonary valve) does not form correctly. (Mayo Clinic, August 4, 2019)

9. **Long QT syndrome (LQTS)** is a heart rhythm condition that can potentially cause fast, chaotic heartbeats. These rapid heartbeats might trigger a sudden fainting spell or seizure. In some cases, the heart can beat erratically for so long that it causes sudden death. (Mayo Clinic, March 21, 2018)
10. **Tetralogy of Fallot** is a very rare congenital heart defect caused by a combination of four heart defects that are present at birth. The four defects are: ventricular septal defect, pulmonary valve stenosis, a misplaced aorta and a thickened right ventricular wall. (Mayo Clinic, March 9, 2018)

11. **Tricuspid Atresia** is congenital in which a valve (tricuspid valve) between two of the heart’s chambers is not formed. Instead, there is solid tissue between the chambers, which restricts blood flow and causes the right lower heart chamber to be underdeveloped. (Mayo Clinic, March 8, 2018)

12. **Ventricular Septal Defect** is a hole in the heart. The hole (defect) occurs in the wall (septum) that separates the heart’s lower chambers (ventricles) and allows blood to pass from the left to the right side of the heart. (Mayo Clinic March 9, 2018)

**Research Questions**

I had several exploratory questions that guided my research.

1. To what extent is there a relationship between children born with a congenital heart defect (CHD) and their being determined eligible for a program under the Individuals with Disabilities in Education Act (IDEA) criteria?

2. To what extent is there a relationship between how long a child has been under general anesthesia and his or her being determined eligible for a program under IDEA criteria?

**Conclusion**

This research topic was extremely important to me as an educator. The previous 29 years of my life were dedicated to educating all children in a public school system. As
I gained more experience as an educator, I quickly realized the unfortunate disadvantage in which children with special needs were always placed. When children were not able to keep up with the curriculum at the same rate as their peers, teachers I observed would become visibly frustrated or simply ignore the student, or draw their own conclusion that the child did not care. None of these responses were acceptable. My research was an effort to bridge the gap in understanding the unseen learning disabilities of children born with CHD. My goal was to bridge the medical professionals with the educational professionals so children born with CHD would be acknowledged and identified to acquire the assistance they needed to be successful academically as young as possible.
CHAPTER TWO

Review of the Literature

This study was designed to examine the relationship of children born with Congenital Heart Defect (CHD) and their being determined eligible to receive services for a program under the Individuals with Disabilities in Education Act (U.S. Department of Education, 2004). This study was also designed to investigate infants and children who have undergone general anesthesia for a prolonged period of time and their rate of eligibility for educational support under IDEA. In this review, I clearly defined CHD and explained the potential effects of having CHD in a child’s life and how it relates to education. Neurodevelopmental outcomes of children, including both long term and short-term memory were investigated in this study. Anesthesia in infancy as well as prior to age two were researched at length.

In an effort to compile the most relevant literature for this study, sources were retrieved from 1979 to 2019. As the most recent journals and articles have a much more advanced approach to the identification of CHD as well as advances in anesthesia, the recent advances allowed me to move forward in disseminating an understanding of the need for an Administrator of Educational & Medical Information in hospitals in each school district of the state under study. Many databases were searched to obtain relevant information for the topic at hand. Topics researched to obtain this information were CHD, general anesthesia and processing, learning disabilities and eligibility, neurocognitive stalling, and exposure to anesthesia. Research was obtained from sources such as American Heart Association, Mayo Clinic, Journal of Pediatrics, U.S. Department of Health, US. Department of Education, U.S. Department of Health and
Human Services, cdc.gov, Shanghai Jiao Tong University, webmd.com, PLOS ONE, ephost@epnet.com, to mention a few of the key contributors.

To conduct my research, I utilized several university databases in the state under which this study was conducted. I used the federal government public databases to secure specific data related to education, socio economic information, and morbidity rates. I also used EBSCO through National Louis University as a primary academia source. For medical terminology and definitions, I utilized the Mayo Clinic online resources for consistency. There were key words used throughout the research phase of my study including Congenital Heart Defect (CHD), CHD Detection, Infant Mortality, Learning Disabilities, Special Education with Heart Defect, Individuals with Disabilities in Education Act (IDEA), Standards Testing and Heart Defect, Behavior and Heart Defects, Anesthesia and Learning Deficits.

**Congenital Heart Defect Defined**

Congenital Heart Defects (CHD) are the most common type of birth defect (American Heart Association, 2018). CHD can vary from mild, such as a small hole in the heart, to severe, such as missing or poorly formed parts of the heart (American Heart Association, 2018). About one in four babies born with a heart defect has a critical CHD. Babies with a critical CHD need surgery or other procedures in the first year of their life (Centers for Disease Control, CDC, 2019). About 97% of babies born with a non-critical CHD are expected to survive to one year of age. About 95% of babies born with a non-critical CHD are expected to survive to 18 years of age (Centers for Disease Control, CDC, 2019). Thus, the population of people with CHD is growing. About 75% of babies born with a critical CHD are expected to survive to one year of age. About 69% of babies
born with a critical CHD are expected to survive to 18 years of age (Centers for Disease Control, CDC, 2019).

During the first six weeks of pregnancy, the heart begins taking shape and starts beating. The major blood vessels that run to and from the heart also begin to form during this critical time during gestation. It is at this point in the baby's development that heart defects may begin to develop. Researchers are not sure exactly what causes most of these defects, but they think genetics, certain medical conditions, some medications and environmental factors, such as smoking, may play a role (Mayo Clinic, 2018).

Signs and symptoms for CHD depend on the type and severity of the particular defect. Some defects have little or no evidence that there is a defect present. Others might cause a baby to have one or more of the following symptoms: blue tinted nails or lips (often called a smurf effect), trouble breathing, tiredness when feeding, and sleepiness (Mayo Clinic, 2019). While not all the symptoms above indicate with certainty that there is a CHD, they may be indicators.

Due to recent advances in technology, primarily with ultrasound imagery, CHD are now being detected during pregnancy. There is a new ultrasound called fetal echocardiography which takes pictures of the heart of the developing unborn baby. However, some CHD are not detected until after birth, during childhood, or during adulthood. Those detected later in life can be determined to be CHD present at birth, not due to later secondary factors (Fetal Medicine Foundation, 2019).

Some affected infants and children do require one or more surgeries to repair the heart or blood vessels. There are recent advances that allow a heart catheterization to be performed to repair problems through the blood vessels. There are times the condition
cannot be corrected, but blood flow can be increased which assists the heart to work more efficiently. The heart catheterization may also allow a physician to take measurements, pictures, and make repairs at a later time (Razzaghi, Oster, and Reefhuis, 2015).

The causes of CHD among most babies are unknown. Some babies’ heart defects are due to changes in their individual genes or chromosomes. CHD also are thought to be caused by environmental factors which may include a mother’s diet, health condition, or medication(s) during pregnancy. Some conditions such as pre-existing diabetes or obesity in birth mothers have been linked to heart defects in babies (American Heart Association, 2018).

**Educational Implications**

There are many potential negative outcomes for children born with CHD as they relate to their educational needs. One of the areas most researched is the academic delays of children with CHD. This subsection highlights studies specifically related to education.

Parents of 76 young people (mean age 15y 8mo) with CHD born at less than 29 weeks’ gestation completed a questionnaire including educational resource information accessed within the previous 6 months. The consensus was that this group was at high risk (>50%) for motor, cognitive, behavioral, and other developmental impairments. Delayed development had an impact on academic achievement, with educational resources and supports required for 30% to 65% in most cohorts (Majnemer et al., 2017).

A study conducted in Arkansas of 362 children who underwent surgery for a CHD were matched to the Department of Education database, 285 of whom had grade 3 and/or 4 achievement test scores. The primary negative outcome was not achieving grade
level proficiency on achievement tests. “Sex, gestational age, age at surgery, CHD diagnosis, and type and number of surgeries did not predict test proficiency. Compared with all public school students, more children with CHD received special education services (26.9% vs 11.6%; P<.001) (Mulkey et al., 2016). This study corroborated my findings of a higher eligibility rate for special education eligibility for children born with CHD.

The National Health Interview Survey was done between 1997 and 2011 to study children from birth to age 17 years with CHD (Schiller, Lucas, Ward, & Peregoy, 2012). Parents were asked whether their child was diagnosed with CHD. Comorbidities were taken into consideration such as autism/autism spectrum disorders, healthcare utilization including number of emergency room visits, and number of days of school missed. These outcomes were compared between children born with CHD and without reported CHD.

The study included 420 children with reported CHD and 180,048 children without CHD. There were no demographic factors studied such as age or sex of the subjects. The study revealed that children with identified CHD were three times more likely to be kept out of daycare/school for more than 10 days in a single school year compared to children without congenital heart defects. Children aged 2 to17 with CHD were more likely than those without CHD to have had a diagnosis of autism spectrum disorder (95% CI) or intellectual disability (95% CI). The rates of emergency room, home and doctors’ office visits were significantly higher in children with CHD (Razzaghi et al., 2015).

A child in need of Special Education services who then actually receives those services is always a concern in the academic world as well as a concern for the parents advocating for their child. A study was conducted in the Atlanta metropolitan area on
children born with CHD from 1982 to 2004. The researchers also considered children without a birth defect born in the same time period. Researchers then linked all these children to data regarding the use of special education services for the 1992 – 2012 school years. The two subgroups were then compared through analyzing the available data. Children with genetic syndromes or birth defects besides CHD were not included in this study. Children with CHD were classified by their type of CHD and whether they had a critical CHD (Riehle-Colarusso, Autry, Razzaghi, Boyle, Mahle, Braun, & Correa, 2015).

The researchers concluded that children with CHD who did not have any other birth defects were 50% more likely to receive special education services compared to children without birth defects. Some of the most common areas of need for services were: Intellectual Disability, Sensory Impairment, Significant Developmental Delay, Specific Learning Disability, and Other Health Impairment (Riehle-Colarusso et al., 2015).

**Anesthesia and its effects on learning.** I questioned whether there was a link to general anesthesia exposure in children and their experiencing learning difficulties when entering school. General anesthesia is a combination of medications that put a person in a sleep-like state before a surgery or other medical procedure. Under general anesthesia, patients do not feel pain because they are completely unconscious. General anesthesia usually uses a combination of intravenous drugs and inhaled gasses (anesthetics). General anesthesia is more than just being asleep, though it will likely feel that way to the patient. However, the anesthetized brain does not respond to pain signals or reflexes (Mayo Clinic, 2018).
A laboratory report from Europe clearly demonstrated that anesthetic and sedative drugs induced both neuroapoptosis and neurocognitive deficits in laboratory models. This issue is of paramount interest to pediatric anesthesiologists and intensivists because it questions the safety of anesthetics used for fetal and neonatal anesthesia. Most clinically utilized anesthetic drugs were found to induce neuronal cell death in the developing brain and to potentially cause long-term neurological impairment (McCann & Soriano, 2019).

A language development study was conducted on children ages 5-18, 53 of whom were healthy with no history of surgery and 53 same age range children who had undergone surgery before the age of 4. “Children Exposed to Anesthesia Scored Significantly Lower in Listening Comprehension and Performance IQ” (Backeljauw, Holland, Altaye, & Loepke, 2015). The language development study coincided strongly with the findings of my study’s population and their eligibility for a program under the IDEA criteria. In my study, 65% of all children surveyed were determined eligible for a program under IDEA including but not limited to the program for children with Language Impairments.

An article written by Moyer (2015) reflected upon an article from the journal of pediatrics titled, “Cognition and Brain Structure Following Early Childhood Surgery with Anesthesia” (Backeljauw et al., 2015). The cause for concern on the part of the author was reflected in this sentence, “Anesthetics induce widespread cell death, permanent neuronal deletion, and neurocognitive impairment in immature animals, raising substantial concerns about similar effects occurring in young children” (p. 136). This article was focused on studies of rats versus humans; however, there was a reference to a Columbia University study from 2011 that stated, “Kids who have undergone anesthesia
under the age of 3 were 60% more likely to later be diagnosed with developmental or behavioral disorders” (p. 3). This statement drew a connection to anesthesia and potential learning difficulties.

An article published by WebMD titled “Anesthesia Before Age 2 Linked to Learning Problems” (Boyles, 2011) did not have a specific study group criteria; therefore, results did not indicate any firm conclusions. However, I found the content to be informative. One of the studies which affirmed my data included children born between 1976 and 1982 in a single school district in Minnesota. A total of 1,050 children were enrolled in a larger health study. A total of 350 children who had one or more surgeries requiring general anesthesia prior to the age of 2 were compared to 700 children with no such history.

There were several major findings from the study as they related to children who had undergone general anesthesia prior to the age of 2 and their ability to learn the same as their unexposed peers. About 37% of children who had multiple surgeries requiring general anesthesia before age 2 had learning disabilities, compared to 24% of children who had just one surgery and 21% of children who had no surgeries. Children who had two or more surgeries prior to age 2 were three to four times as likely to have been identified by their schools as needing special help for language and speech difficulties through an Individual Education Plan (IEP). This finding coincided with my study which yielded a 50% eligibility rate for the Language Impaired and Speech Impaired Programs combined.

An article titled, “Surprising New Study Reveals Dangers of Anesthesia in Kids” (Duhaime-Ross, 2014) gave a synopsis of a study done at the University of California
San Francisco by Greg Stratman, anesthesiology professor. Stratman said, “Anesthesia in kids is not harmless” (p. 2). Stratman and his team investigated the recollection abilities of 28 children age 6 to 11 who had undergone general anesthesia before age 1. Children were shown 80 drawings with varying border colors and locations on a computer screen. Five minutes later, the children were asked to point to the drawings they saw from a set of 160 drawings with the colored borders removed and locations changed. “We found that for color details, anesthetized kids scored 20 percent less correct answers than unanesthetized kids” (Duhaime-Ross, 2014, p. 2). As this was a limited study, there did appear to be quite a difference between the two groups of children with the one variable of anesthesia before age 1 having been documented.

**Conclusion**

To fully embrace the need for the Administrative Educational/Medical Professional position in the medical sector, several understandings must be in place. One must have a comprehensive understanding of what CHD is. One must also understand how anesthesia may potentially impact the brain’s development, and the educational implications for children with CHD who have undergone general anesthesia.
CHAPTER THREE

Methodology

Research Design Overview

My evaluation focused on children born with a Congenital Heart Defect (CHD) having undergone prolonged periods of general anesthesia and then being determined eligible for a program under the Individuals with Disabilities in Education Act (IDEA). I used a utilization-focus based on the work of Patton (2008). I collected data by using a survey assuring anonymity of all participants. I gathered surveys during speaking engagements with the target audience who were parents of children born with CHD throughout the state of the study.

Utilizing the audience to which I had access, I was able to keep the scope and sequence of my data pure without any outliers. The parents of the children born with CHD were eager to learn as much as possible to assist their children in their education. I explained my study to them, and in turn, by their agreement to provide me the information and give me consent to use it, I, could guide them through the educational process to assist their children. These data were real time data from the people living the challenges with their children, and this was why I believed my research questions were answered with fidelity.

The research questions were:

1. To what extent is there a relationship between children born with a congenital heart defect (CHD) and their being determined eligible for a program under the Individuals with Disabilities in Education Act (IDEA) criteria?

2. To what extent is there a relationship between how long a child has been under
general anesthesia and his or her being determined eligible for a program under IDEA criteria?

**Participants**

The key participants in this study were children born between 2002 -2019 who were diagnosed with CHD in the state under study who were participants in the American Heart Association Heart Heroes Program. Typically, these children were diagnosed at birth; however, CHD is not discovered in some children until later in life. The most significant defects are clearly visible at birth due to low or no oxygen creating the “blue baby” due to lack of oxygen in the blood.

This audience was chosen due to my personal involvement with the American Heart Association Heart Heroes (AHAHH). My involvement with the association began with its inception in 2002. I became involved through a friend who was the head pediatric cardiology nurse at a nearby hospital in the United States. The main reason I became involved was both of my parents died young from complications with their heart in 1991 and 1992. I made it my goal to learn about what happened to them and to do what I was able to do to prevent myself from the same demise.

**Data Gathering Techniques**

I gathered data using a survey that was not able to be traced to specific individuals. As I began my presentation to the parents on navigating the school system for their child, I explained who I was and that I was gathering data for my dissertation. An actual survey was distributed to the parents and I explained and reiterated that all information was confidential and that if they would like me to send my results via email, they could provide their email address. All surveys were collected by the American Heart
Association Heart Heroes and given to me (Appendix A).

I distributed the survey and collected responses during speaking engagements and also via email obtaining confirmation from each family to utilize data obtained via the American Heart Association with the target audience, which were parents of children born with CHD throughout the state under study. This survey was paper based. The second modality was the same exact survey available online with the American Heart Association Heart Heroes (AHAHH).

Through the survey, I requested information from the parents to the best of their recollection and knowledge. There was not a possibility of my breaching Health Insurance Portability and Accountability Act (HIPAA) because all information I collected via parent report and not through medical records. The main function of HIPAA is to protect confidential medical records which, for the purposes of this study, were not accessed and did not need to be accessed due to parent reporting.

**Data Analysis Techniques**

To analyze the data from the surveys, I conducted a quantitative analysis to ascertain the relationship of children born with CHD having undergone general anesthesia and being determined eligible for a program under the IDEA. I then disaggregated the data collected to obtain a breakdown of which programs under IDEA for which the children were determined eligible. I looked for trends as well as commonalities for further study.

Throughout my review of the relevant literature, I was able to find commonalities among previous studies to my findings in my research. A specific study conducted in Arkansas revealed a 15% higher eligibility rate among children with CHD compared to
other children for special education services (Mulkey et al., 2016). The data gathered in my study showed a 30% increase among children with CHD compared to other children in being determined eligible for special education services with a much smaller population surveyed.

**Autoethnography**

An additional element of my data collection included my reflections of my personal and professional experiences in public education. I included actual scenarios within disability categories in an effort to bring more clarity to the eligibility requirements and the varied data and diagnoses required. The term for this type of research is autoethnography. Autoethnography was defined by Mills, Eurepos, and Wiebe (2010) this way, “Autoethnography is a form or method of research that involves self-observation and reflexive investigation in the context of ethnographic field work and writing” (p. 43). The retelling of specific cases under each program in IDEA was imperative for the reader to have a more comprehensive understanding of each disability area. The ability for the reader to understand the disabilities and how they affect children and their ability to learn was why the autoethnography was vital to the data I collected.

**Ethical Considerations**

All data gathered were provided by the parents/guardians of the children of their own free will. There were no identifiable questions on the survey; therefore, no one could track the participants. All participants gave written consent for the information to be used for my study. I did not interact with any children at any time during this study; only the parents/guardians had an opportunity to ask questions of me during or after the presentation.
I assured confidentiality to all participants involved in my study. I gathered data during speaking engagements with the target audience, who were parents of children born with CHD throughout the state of the study. This survey was paper based. The second modality was the same survey available online with the AHAHH. I emailed every family for whom I had the contact information that was obtained via the American Heart Association and only utilized those surveys for which I had written approval to use.

**Limitations**

One of the main limitations to the data I collected was that I gathered subject information only in the state of the study. The AHAHH is an initiative in the Southeastern United States that offers assistance to families specifically of children born with CHD. Primarily, the pediatric cardiologists and their nurses attempt to inform parents of children born with CHD of resources available to help them with their newborn, medically fragile children. It is up to the parents to make contact with the AHAHH to become a part of the support group. Family Conferences for the AHAHH are held in the spring and the fall in different regions of the state under study. There are sessions for two days for the parents that cover topics such as long-term insurance needs, modern advances in surgical procedures, early identification, and new discoveries in treatment and education. While the parents attend their sessions, the children born with CHD and all siblings are educated about their (or their siblings’) CHD while enjoying fun activities conducive to children born with CHD.

I speak at every conference on how to navigate the school system for the child born with CHD. I discuss in detail in how to access early identification programs and transition programs in school. I also educate the parents on the differences between a
Section 504 plan and an Individualized Education Plan (IEP). A limitation was that only those parents who attended the conference weekends fully understood the purpose of my study and had the opportunity to complete a paper-based version of the survey. Another limitation was that many who attended a conference had children who were new-born and they were just beginning to understand how to keep their child alive; looking down the road to their child’s education was not on their mind at this point in their journey as a parent of a child with CHD.

A limitation of the data gathered was also the variability within each school district in the state of study in determining eligibility for a program under IDEA. There were federal guidelines to consider regarding eligibility criteria; however, there was not a “first/then” model in determining a child eligible for a program. In other words, there was not an objective tool available for consistency and continuity on eligibility. There was a lot of subjectivity and areas left open to interpretation when it came to interventions and eligibility procedures from school district to school district. While this was a single state study, there was a lack of cohesiveness among school districts across the state in determining a uniform procedure and protocol for identifying children eligible for a program under IDEA and receiving educational assistance.

**Conclusion**

It was overwhelming to receive such an amazing response to the request for information from parents on their children born with CHD. Every family was more than willing to provide me with the information requested. Every family also asked to receive the results of the study, so they would have this information to assist them in advocating for their children in their education. Due to the willingness of these families, 43 responses
were obtained to yield the results discussed in the next chapter.
CHAPTER FOUR

Results

In this section, I presented the results of my research. The data I gathered was completed voluntarily by the families of children born with Congenital Heart Defects (CHD) through the American Heart Association Heart Heroes Association (AHAHH). Based on my experience, there were no limits for the families of children with CHDs in their drive to do everything in their power for their children. Faced with the unthinkable, in some cases before birth and in most cases immediately upon birth, parents made decisions in a split second for their child’s survival. After this time had passed, it was now the family’s opportunity to raise their child to the best of their ability with any information they could utilize to assist them. My goal was to bridge the gap between the medical world and the educational world to understand and embrace our children born with CHD and to help them succeed. This study included parents of children born with CHD across one state in the United States.

Findings

I collected 43 surveys for the purposes of this study. Parents of children born with CHD reported the following information for data gathering purposes.

<table>
<thead>
<tr>
<th>Parent Data Reported</th>
<th>Data Obtained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre - school age</td>
<td>6</td>
</tr>
<tr>
<td>No disability</td>
<td>12</td>
</tr>
<tr>
<td>IEP</td>
<td>16</td>
</tr>
<tr>
<td>Section 504 plan</td>
<td>8</td>
</tr>
<tr>
<td>Gifted</td>
<td>1</td>
</tr>
<tr>
<td>Anesthesia prior to age 3</td>
<td>14</td>
</tr>
<tr>
<td>Anesthesia after age 3</td>
<td>1</td>
</tr>
<tr>
<td>No anesthesia</td>
<td>1</td>
</tr>
<tr>
<td>Youngest age under anesthesia</td>
<td>Birth</td>
</tr>
</tbody>
</table>

Figure 1. Data reported and incidences of each data occurrence (n = 43)
I disaggregated the data obtained, subtracted pre-school age children, children with a section 504 plan, gifted children, and children who had not been identified under the Individuals with Disabilities in Education Act (IDEA) criteria. My data revealed 43% of children born with CHD who had general anesthesia had been determined eligible for a program under the IDEA criteria. Based upon the data gathered, a child born with CHD was 30% more likely to meet eligibility for a program under IDEA than his or her school age peers based on previously reported information. In 2013-14, the number of children and youth ages 3-21 receiving special education made up about 13% of all public school students (Kena, et al., 2016).

Fourteen of the 16 children of participants in my study who had Individual Education Plans (IEP), or 87.5%, underwent general anesthesia prior to the age of 3. The youngest reported child to undergo surgery was at birth. Of the 14 children of participants in my study who had an IEP, the total number of hours under anesthesia was 359 with the average number of hours under anesthesia being 22.4 hours. The most hours combined under general anesthesia in a child’s life to date was more than 50 and the least number of hours was four. Of the 14 children with IEPs, the total number of surgeries and general anesthesia due to the CHD was 72 with an average of 5.14 hours of exposure to general anesthesia per child.

Under the IDEA criteria, as mentioned previously, there were 13 possible programs for which a child could meet eligibility criteria to receive services in his or her educational setting. Children can and often are determined eligible for more than one program; therefore, the numbers of programs for which children are eligible do outnumber the actual number of subjects. Of the subjects reported in this study, eligibility
criteria were met for five of the 13 possible programs. The most prevalent program was Speech Impaired with seven or 44% of children of participants (subjects) who were eligible, Other Health Impaired with 10 or 62.5% of subjects eligible, Autism Spectrum Disorder with two or 12% of subjects eligible, Specific Learning Disability with two or 12% of subjects eligible, and Multiple Disabilities with five or 31% of subjects eligible. In comparison to the national percentage of children meeting eligibility for Specific Learning Disabilities which is 34%, among children with CHD, 12 were eligible. There was a considerable discrepancy between the overall percentage of children with CHD meeting eligibility for the Specific Learning Disabilities with a 12% eligibility versus the national average percentage of 35%; however, such children met eligibility for many different programs at a 30% rate overall.

This study demonstrated the relationship between anesthesia exposure during infancy among children with CHD and learning disabilities identified among children with CHD, as also documented in a Mayo Clinic study conducted in 2009 by Taylor who said, “Infants who had just one exposure to anesthesia showed greater risk of having learning difficulties. Those with two or more exposures had a 60% increased chance of learning disabilities compared to those who had no surgeries” (pp. 1381-1382). There are many ways to define a learning disability; however, for the purpose of this study, I chose to use the definition under IDEA as follows:

The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. The IDEA governs how states and public agencies provide early
intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities (U.S. Department of Education, 2020, p. 1).

The relationship of children born with CHD and their attendance in school is another potential barrier to learning. Attendance in school is imperative to learning grade level standards (Razzaghi et al., 2015, p. 116). When a child is too sick to attend school, he or she is often determined eligible for programs under the IDEA criteria such as Other Health Impaired (OHI). The OHI program definition is: “OHI covers conditions that limit a child’s strength, vitality or alertness including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems” (U.S. Department of Education, 2017). As published in the Journal of Pediatrics, the study findings by Razzaghi et al. included that 420 children with reported CHD and 180,048 children without CHD. The odds of reporting worse health and more than 10 days of school/daycare missed in the previous year were three times higher for the children with CHD compared to those without CHD. (2015, p. 116)

Another discovery in the study showed, “Children born with CHD were more likely than those without CHD to have a diagnosis of Autism Spectrum Disorder or Intellectual Disability” (Razzaghi et al., 2015, p. 116). The most prevalent eligibility in this study was for the Other Health Impaired Program with the second highest eligibility program being for the Speech Impaired program.

The data I gathered through the AHAHH confirmed there was a significant relationship between children born with CHD having undergone general anesthesia prior
to the age of 3 for longer than four hours and being determined eligible for a program under the IDEA criteria. The national average of children determined eligible for a program under the IDEA criteria is 13% which is significantly lower than the 45% determined eligible in my study who were born with CHD. Based upon this study, there is a relationship between children born with CHD and being determined eligible for a program under IDEA.

**Context.** One of the biggest barriers to school leaders in obtaining valid data on anything medical is the Health Insurance Portability and Accountability Act (HIPAA) of 1996 which are regulations protecting the privacy and security of certain health information (U.S. Government Legislation, 1996). A major goal of the security rule is to protect the privacy of individuals’ health information, called Protected Health Information (PHI). Embedded in this rule is also a subsection which states parents are not obligated to disclose their child’s medical information to anyone, including schools.

Educators can only meet the needs of their students if there is a clear understanding of potential influences to the child’s ability to learn. As I have experienced, often times, parents choose not to divulge critical information about their child out of fear their child may be treated differently or unfairly. When a child has a medical condition that can potentially affect his or her ability to learn, it is most prudent for this information to be shared with educators. Unfortunately, educators do not have the right to request medical information, nor does the parent have a legal obligation to provide information per HIPPA (U.S. Government Legislation, 1996).

When a pediatric cardiologist is involved with a family of a child with CHD, he or she is not obligated or expected to share this information with the child’s educational
institutions per HIPAA (U.S. Government Legislation, 1996). This lack of reporting makes it difficult for a school system to be able to make educated decisions on behalf of the student. As a veteran teacher and district level administrator of more than 30 years, I witnessed many families become frustrated with their child’s school guidance counselor, assistant principal, principal, or whoever they had spoken to about their child’s struggles academically. As a district level administrator responsible for 11 programs and related services for children in Exceptional Student Education (ESE) Programs, I worked daily to assure all children’s needs were addressed. In my experience, medical conditions such as CHD were often viewed as a silent contributor to a child’s difficulty in mastering grade level standards. When a child had no visible differences than his or her same age peers, the child was often viewed as defiant or willfully uncooperative when he or she displayed inappropriate behaviors. In my experience, this perception of children sometimes led to them not having their needs met due to medical information not being required as this could and often did carry the missing link to assisting the student academically.

Another potential barrier in obtaining data specific to CHD and learning difficulties is the protection under HIPAA that prevents physicians from sharing information that may be beneficial for educators to have. As the medical profession has a specific purpose in the child’s well-being, so does the educational profession. There was not reliable data at the point of my study showing an effort on the part of medical professionals to obtain information from families on their children’s educational challenges and successes.

There was also a variable in children being properly identified as a child with CHD as socio-economic class and the ability to secure pre-natal and post-natal care were
dependent on income. Families that were not able to seek medical care as readily as a more affluent family, may have had children with an undiagnosed CHD. This, in itself, can lead to skewed data. However, pre-natal diagnoses of CHD were becoming more common. When families with low socioeconomic conditions could not acquire this medical attention, children were born without parents and medical professionals having prior knowledge of the defect which led to a higher morbidity rate in infants (Tuan, 2017).

**Culture.** In education as a whole, the overarching goal is to educate every child to the best of his or her ability. While educators have standards in every subject and at every grade level to teach children, not all children learn the same way and not all children possess the same ability to learn at the same pace or with the same rigor. Education leaders and parents expect teachers to differentiate their instruction to meet the needs of all learners; however, this is extremely difficult if pertinent information is not shared about their students. In my professional experience, pertinent information, such as medical conditions that could and often did impede a child’s ability to process academic information, was imperative for educators to have to help every child reach academic success.

Educationally, there were required procedures created by the federal government as well as state and local policies and procedures to aid in the identification of struggling students. The IDEA re-authorization of 2004, governed how states and public agencies provided early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.

In a perfect world, teachers would be provided the opportunity to learn about their
students prior to receiving them for the academic year. Though teachers have had the ability to discuss students and their academic successes and struggles among themselves, most have not had the time to do so due to time constraints in their teaching schedules. Added to this, there was no obligation on the part of the family to divulge medical information that may have been a contributing factor to a struggling student, and meeting their needs academically became a monumental task for the classroom teacher. When there was no medical information available and a student was struggling academically, a “needle in a haystack” approach was often used to find why the student was struggling to learn. When this happened, it could take months, or years to determine through interventions what needed to be done for the student to learn at the same level as his or her peers who did not have CHD.

Taylor (2009) stated children who have undergone general anesthesia are more likely to display delays in processing and inappropriate behaviors due to a chemical change in the brain during development in utero. Taking this information into consideration, it was extremely difficult for teachers to meet the needs of these students when they did not possess the medical information necessary to properly assist the children. This is where the Multi-Tiered System of Support (MTSS) was useful as “an instructional framework that includes universal screening of all students, multiple tiers of instruction and support services, and an integrated data collection and assessment system to inform decisions at each tier of instruction” (Sedita, Sedita, & Sedita, 2018.). In the state in which the study was conducted, the Multi-Tiered System of Support was required for all children in the public education system.
Conditions. The complexity of CHD being diagnosed was dependent on pre-natal as well as post-natal identification and care for the fetus and infant. If the ability to diagnose and treat those born with CHD existed, the outcomes for those born with CHD were vastly improved. Due to the dramatically varying care available throughout the state, the data I collected was not completely indicative as an absolute identification for statistical relevance.

In the United States, we have an extreme imbalance of medical care based upon socioeconomic status.

The high U.S. infant mortality has some association with and may be attributable in large part to disparities in socioeconomic status which in turn are associated with race and ethnicity. ... The Southeastern states’ average infant mortality rate has been approximately 7 deaths per 1,000 live births in recent years. (Mwaniki, 2018, p. 5)

According to the Mississippi State Department of Health (2017) and Alabama Department of Public Health (2017) 8.8 and 8.9 babies per 1,000 born in 2012 died before their first birthday, respectively. This issue made the infant mortality rate in Mississippi and Alabama more comparable to those of developing countries such as Chile (8.0 per 1,000 live births), Lebanon (8.0 per 1,000 live births), and Oman (10 per 1,000 live births) than that of the U.S. (6.0 per 1,000 live births), according to latest estimates from the World Health Organization (2015).

An estimated minimum of 32,000 infants were expected to be born with CHD each year in the United States. Of these, an approximate 25%, or 250 children per 1,000 live births, required invasive treatment in the first year of life. When this treatment was
not available or affordable, the infant became a mortality statistic. Congenital heart defects were the most common cause of infant death resulting from birth defects; 27% of infants who died of a birth defect had a heart defect (American Heart Association, 2013, pp. 1-5).

The most commonly reported incidence of congenital heart defects in the United States was between 4 and 10 per 1,000, clustering around 8 per 1,000 live births. Congenital heart defects were the most common cause of infant death resulting from birth defects; 27% of infants who died of a birth defect had a heart defect. The 2009 death rate attributable to congenital cardiovascular defects was one. Infant mortality rates (<1 year of age) were 31.4 for White infants and 42.2 for Black infants (American Heart Association, 2013, pp. 1-5).

**Competencies.** The first hurdle I noted in this study was the ability for all educators to gain a comprehensive understanding of the different types of CHD. A CHD is not an “if/then” issue. In other words, it is a condition that when addressed through life saving surgical procedures, will lead to challenges in learning. The question is actually about severity and where the child falls on a spectrum of the severity of the condition and how that will impact his or her ability to learn. For instance, to state a child has a Ventricular Septal Defect, does not imply there is a severity factor to the identified CHD. There is a plethora of diagnoses which fall under CHD. Per my experience in public education, it was virtually impossible for an educator to be able to have a comprehensive understanding of all and how they might impact a child’s ability to learn.

There was a lack of competent understanding of the protection of the child/family under the HIPAA of 1996. Parents had the right not to divulge medical information about
their child. In my experience as an educator, this was often the most difficult bridge to cross. I have personally dealt with families not wanting to share medical information about their child out of fear their child would be treated differently than their non-disabled peers in the general education population. Due to HIPAA, school leaders and other educators did not have the ability to seek information unless there was written consent from the parent.

Parents of students with special needs often had a misperception that all teachers know about all areas of education including special education. Teachers were masters of the content and strategies needed to deliver effective instruction in their current classroom, most effectively to the non-disabled student. Special Education curriculum specialists were available to assist in the process to help teachers navigate the system should a child need assistance that reached beyond the teachers’ current strategies in their classrooms. The eligibility criteria under IDEA were specific and typically not understood by the general education classroom teacher, based on my experience as an administrator in Exceptional Student Education.

When a child was struggling academically and the family had not shared important information about a potential medical contributor to the academic difficulty, children, in my experience as an educational leader, could be viewed as “difficult” or “uncaring.” If the child had undergone general anesthesia for a prolonged period of time prior to the age of 3, there was the potential for their ability to process information to be diminished (Hollenbeck, Grout, Smith, & Scanlon, 1986). At the time of my study, there was limited research available to determine whether the actual anesthesia was the main contributing factor to the child’s difficulty learning. There were many studies on
anesthesia; however, due to the subjectivity and eligibility criteria variables, there was not a clear understanding of how anesthesia specifically impacted the eligibility for a program under IDEA, at the time of my study and based upon my research.

**Interpretation**

In 2013-14, the number of children and youth ages 3-21 receiving special education services was 6.5 million, or about 13% of all public school students. Among students receiving special education services, 35% had specific learning disabilities while the remaining 65% had varying representation from the remaining 12 programs under IDEA (Kena et al., 2016).

The Individuals with Disabilities Education Act (IDEA) listed 13 different disability categories under which 3-21-year-olds were eligible for services. These categories were:

- autism
- deaf blindness
- deafness
- emotional disturbance
- hearing impairment
- intellectual disability
- multiple disabilities
- orthopedic impairment
- other health impairment
- specific learning disability
- speech or language impairment
- traumatic brain injury
- visual impairment (including blindness)

The IDEA required public schools to provide *special education* and *related services* to eligible students. But not every child who struggled in school qualified. To be covered, a child’s school performance had to be “adversely affected” by a disability in one of the 13 categories listed above. In the next subsections, I provided definitions and examples from my professional experience in public education. All vignettes I provided are real life scenarios that happened in public school grades K-12. I intended these scenarios to provide a more comprehensive understanding of each disability.

**Specific learning disability (SLD).** The umbrella term SLD includes a specific group of learning challenges. These conditions affect a child’s ability to read, write, listen, speak, reason, or process mathematics. Such conditions may include:

- Dyslexia
- Dysgraphia
- Dyscalculia
- Auditory processing disorder
- Nonverbal learning disability

SLD was the most common category under IDEA. In 2018, 34% of students who qualified did so under this category (Kena et al., 2016). In my personal and professional experience, I attended meetings where this diagnosis has been difficult to define. One such meeting was for a child who was struggling to write. The teacher shared how if the child could just listen and then respond verbally, he would typically earn an A. Anytime he had to write a response, the teacher couldn’t read anything he wrote, so he received
failing grades. I spent several days observing and working with this student to learn about him. Every time he was asked to write anything, he either searched in his desk or asked to go to the restroom, anything to not have to write. When the teacher asked the students to work together, he always avoided showing his paper he had written to his classmates.

As I attempted to work with him one on one, he was resistant. After a couple of days of just talking to him, getting to know him, he tried to write with me. It was blatantly obvious he knew the alphabet; he could read, he could sound out words, but his hand just couldn’t form the letters he could say. We used an alphabet line to attempt to help him have a visual cue to form the letters. His frustration continued to grow as he attempted to write. I then introduced using a keyboard to produce written work. After some practice, the student became comfortable with the keyboard and began “writing” his responses without attempting to avoid the task. This child clearly had dysgraphia. His motor planning, and his ability to get his thought from his head to the paper via a writing implement was extremely stressful and often impossible. Due to the teacher having gathered data before and after the interventions were in place, the student was determined eligible for the Specific Learning Disabilities Program.

Other health impairment. The umbrella term “other health impairment” (OHI) covers conditions that limit a child’s strength, vitality or alertness including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems (U.S. Department of Education, 2017). One example of this is Attention Deficit Hyperactivity Disorder (ADHD), which impacts attention and executive function. Another common example of OHI is a student who suffers from asthma. A child with asthma may have
times during the school year when he or she is on medications that cause him or her to shake, become thirsty, lethargic, or unable to concentrate which impacts the ability to focus or concentrate (Kena et al., 2016,).

In my personal and professional experience, this program was often viewed as a “catch all” program in which almost any medical diagnosis met the criteria for eligibility. I worked with an elementary age student who struggled to remain on grade level academically. She was at the top of her class the first few years of school; however, as she entered fourth grade, her grades began to decline. The teacher sent home notes to the parent about how the child did not appear to be putting forth her best effort. The teacher reached out to the school guidance counselor for assistance in developing strategies to meet the student’s academic needs. After observing the child in the classroom setting, the guidance counselor called me for assistance.

The guidance counselor asked me to observe the child to help determine why she was struggling. After spending some time in the classroom, one thing was clear, the student was struggling to follow along and oftentimes appeared to daydream. I kept track of her times off task and then asked the guidance counselor and teacher to keep tally marks with approximate time and length of the student’s periods of daydreaming. After approximately three weeks, we reconvened to discuss the data. It was quite obvious the child was not daydreaming, but rather she was disconnected from the class. My professional experience led me to believe the girl was having seizures in class. We scheduled a meeting with the parents to discuss our findings. The parents shared they had noticed a change in their daughter as well. The committee recommended to the parents they consider taking their daughter to their pediatrician.
The parents followed up with their pediatrician who then referred them to a pediatric neurologist. The school leaders obtained a release by the parents to share their data with the neurologist. The little girl underwent a sleep study to look for seizure activity in the brain. The little girl was diagnosed with a seizure disorder and received treatment immediately. Due to this diagnosis, she was eligible for an Individualized Education Plan to have strategies and accommodations in place for her to be successful academically.

**Autism spectrum disorder (ASD).** ASD is a developmental disability. It covers a wide range of symptoms, but it mainly affects a child’s social and communication skills. It can also impact behavior (Kena, et al., 2016). In my personal experience, the journey began in 1997 with my son entering kindergarten. He entered kindergarten reading chapter books and adding and subtracting three-digit math problems. Within the first four weeks of school, my husband and I witnessed him become frustrated, angry, withdraw from class activities, and withdraw socially from his peers. He was very articulate and told us how bored he was, gave examples of coloring in pictures and repeating letters of the alphabet. I met with the principal and asked him to please allow my son to go to a first-grade class for Language Arts and math but to remain with his age appropriate peers for everything else. The principal told me many parents think their children are advanced, and that I just needed to be patient.

Less than two weeks later, the teacher called and asked if I would sign a consent to have my son tested for eligibility for gifted services. I agreed to go to the school for a meeting to discuss my son and his needs. During the meeting with the teacher, principal, and school psychologist, my husband and I shared our concerns about our son’s academic
needs not being met. The teacher shared her concerns about his lack of social skills with his peers. We reiterated the reason for requesting he go to first grade for part of the day; however, remaining with his age appropriate peers the rest of the day to gain social skills. We were denied this request; however, we agreed that I would send in packets of course work, at the academic level he could complete, every Monday for the week for Language Arts and math.

I provided packets of work to the school each Monday for four Mondays until someone called and asked us to come in for the results of the psychoeducational testing to determine if he met eligibility for the gifted program. When we entered the meeting, the principal delivered a very humble apology about not listening to us in the beginning of the year. Our son had tested more than three standard deviations above the average range for Intelligence Quotient, and indeed, he was highly eligible for the gifted program. Due to his score being so high, the principal then asked us if we would be willing to skip kindergarten and place him immediately in the first grade. We did place him in first grade which then made him the youngest child in the class, and he struggled socially even more than in the kindergarten class.

As he continued to grow academically, the social component did not grow at the same pace. Entering grade 4 was very emotional for him; he became very unsettled, and did not want to go to school. He never wanted birthday parties for himself and he didn’t like going to anyone else’s birthday party. It was at this point we sought help from a psychologist specializing in youth to help us understand why he struggled emotionally. After several testing sessions, our son was diagnosed with Asperger’s Syndrome on the
Autism Spectrum. He was also diagnosed with dysgraphia, attention deficit disorder (ADD), and obsessive-compulsive disorder (OCD).

Our son was determined eligible for an IEP for Other Health Impaired based on the diagnosis of ADD which allowed for accommodations. His diagnosis of Asperger’s was noted; however, at the time, not understood by many educators. The diagnosis of dysgraphia was acknowledged, and accommodations were written on his IEP. When he entered middle school, the educators included an accommodation on his IEP that permitted him to use a keyboard for written assignments. When he entered middle school, he used a keyboard for written assignments. The diagnosis of Asperger’s Syndrome gave us the opportunity to learn about what it meant for him as a person and how we needed to meet his needs as a family. As the years went on, the IEP was dismissed, a section 504 plan was implemented, and eventually he earned his master’s degree and founded a nonprofit business in the Netherlands.

In my professional experience, I witnessed educators who had various opinions on the meaning of “autism” and how it presented in children. I attended meetings with parents and school personnel for children from ages 3-22. I attended meetings in which a parent arrived with a medical diagnosis from a doctor that a three-year-old was diagnosed with autism. The child had been home with family and had never been in an academic setting, yet the parents insisted their child needed an IEP. The education professionals at the table did not deny or disagree with the doctor’s diagnosis, they simply had never met the child to determine if the child needed an Individualized Education Plan (IEP). One of the key pieces of information in determining eligibility for any program is how the child functions in the classroom setting.
It is exceedingly difficult to determine a child eligible for an education plan based on a medical diagnosis when there is no evidence to determine at what level the child functions academically. Behaviorally, there are indicators that a child will need additional assistance beyond that in a conventional classroom. If the behaviors are extreme at the age of 3, a child can be determined eligible for an IEP; however, the academic needs must be determined through copious data collection. Interventions must be implemented and documented in the classroom setting as part of the consideration for academic assistance on an IEP.

**Emotional disturbance.** Various mental health issues can fall under the emotional disturbance category. They may include anxiety disorder, schizophrenia, bipolar disorder, obsessive-compulsive disorder, and depression. Some of these may also be covered under other health impairment (Kena et al., 2016). During my professional experience in public education, this was always the most difficult program in terms of determining eligibility for a child. When a child displayed inappropriate or negative behaviors that were significantly different from their peers, they were often perceived as willful. I participated in many meetings such as IEP meetings, teacher/administration, and parent/teacher/administration meetings in which we discussed concerns from parents and school leaders regarding students’ behaviors. I attended one particular meeting after a parent contacted me due to concerns for the daughter.

The daughter took honors classes and two tenth grade classes while in ninth grade due to being advanced academically. The daughter had never struggled academically or socially in school; however, she was now struggling in both areas. We scheduled a parent-teacher conference to discuss concerns and gather information from the teachers.
As teachers provided their overview of the student’s performance in class, a pattern was identified. The student was not completing any work during class time but eventually turned it in completed, and teachers accepted it. She also had a difficult time completing tests during the allotted time. The teachers also all agreed she was a quiet, compliant student with a few friends but was not outgoing.

As was my practice with older students, after the adults had an opportunity to speak openly, I brought the student into the meeting. We were careful in our presentation of what we discovered as patterns and asked for her input. We asked the student if there was anything we could do to help her during classes to help her complete work. She was very forthcoming and said she became nervous and afraid she would not finish her work, so she just waited until she knew she had time to do it to her best ability. She also said she froze on tests out of fear she would not finish, and then she could not think clearly and actually did not finish the tests.

This meeting was instrumental in the child’s academic career. Her parent listened intently to her and took her to their doctor seeking assistance. They were guided to a child psychiatrist, and their daughter was diagnosed with an anxiety disorder. Increased anxiety was not uncommon when transitioning to high school as the demands academically and socially increased quickly. The committee reconvened and determined the student eligible for the emotional disturbance program which allowed for accommodations to mitigate her anxiety. She graduated high school with high honors.

**Speech or Language impairment.** This category covers difficulties with speech or language. A common example is stuttering. Other examples are trouble pronouncing
words or making sounds with the voice. It also covers language problems that make it hard for children to understand words or express themselves (Kena et al., 2016).

In my professional experience, I recognized children who struggled with their speech and brought it to the attention of the Speech Language Pathologist (SLP). When I heard children unable to pronounce words correctly, the first thing I considered was the age of the child, as there were developmental guidelines for specific speech sounds. There was occasionally the obvious lack of speech upon entering kindergarten which was a bigger concern. At one point, I was called by a parent and asked to assist her in advocating for her son.

I immediately asked for a copy of her son’s cumulative file from the school system. Upon receipt of the file, I created a timeline of his IEPs. Her son was determined eligible at the age of 3 for an IEP as a student with developmental delays. One of the areas emphasized was his lack of speech in general; he made no effort to speak. An evaluation was completed, and he was determined eligible to receive therapy to address his inability to communicate his basic wants and needs. He was introduced to a picture exchange vocabulary system (PECS) through which he pointed to pictures to represent responses.

The PECS strategy was also implemented to address his language deficit. Language is vastly different than speech, as language is the ability to process information and respond appropriately within context. His language deficit was so great that he was eligible to receive therapy for language, as well as speech. The language deficit also interfered with his ability to learn grade level concepts.
The child had an IEP for four years and received direct therapy services for both speech and language. He used PECS on a limited basis to communicate. He was a sweet and compliant child; therefore, he had been unnoticed previously. Then the student was dismissed from his IEP and stopped receiving all services. He was in second grade, nonverbal (did not speak), the teacher had to learn to interpret his facial expressions to understand what he was attempting to communicate and to know his needs/wants. We previously held a meeting to place him on a section 504 plan with services for speech and language therapies, as well as accommodations in the classroom. We also had a signed consent from the parent for a full psychoeducational assessment to determine his eligibility under the IDEA.

This was an ongoing case for the school system at the time of my study. The child was undergoing psychoeducational testing and data was being compiled. Once this process was completed, an IEP meeting would be scheduled to discuss the results and determine if the child was eligible for a program, and if so, then determine the most appropriate program to meet his needs.

**Visual impairment, including blindness.** A child who has eyesight problems is considered to have a visual impairment. This category includes both partial sight and blindness. If eyewear can correct a vision problem to 20/70 or better, then the student does not qualify for the program (Kena et al., 2016).

I was the program specialist over this program, and therefore, I was responsible to ensure all children in the program received their curriculum in the modality in which they could access the curriculum successfully. Many children with a visual impairment needed the print to be larger so they could see it. In some cases, using a magnifier was preferred.
Some students preferred textbooks with larger print. Textbooks with larger print could require six to eight volumes to include all the content.

I worked with a little girl in elementary school who was in the program for children with visual impairments. She met the medical parameters to be considered legally blind with her corrective lenses. Visual acuity of 20/200 means that what the legally blind person can see at 20 feet, the average person can see clearly at 200 feet. She preferred to have textbooks with large print to access her curriculum. Because of her status of being legally blind, educators were obligated to teach her Braille. She really did not like Braille because she felt she could “see” and did not want to be different than her peers.

During her fourth-grade year, when school resumed in January after winter break, the student was absent with doctor’s permission due to having undergone surgery during the break. Approximately two weeks later, she returned to school, blind. The surgery was to remove lenses from her eyes due to swelling behind the lenses. The lenses would remain removed for several months to attempt to reduce the swelling, and then she would receive new lenses in her eyes. The state-wide assessments were approaching, and the student could not see to complete the assessments. Her Braille was rudimentary and not functional for the state assessments.

The anxiety of the little girl grew each day as the assessment window drew nearer. I contacted leaders at the department of education to request a special exemption for her from the assessments. I explained to the superintendent the rationale for requesting the exemption, he approved, and the request was granted by the state leaders.
During the summer, the student received new lenses and was technically able to see again; however, she still qualified for the program for children with visual impairments.

**Deafness.** Children with a diagnosis of deafness fall under this category. These are children who cannot hear most or all sounds, even with a hearing aid. These children rely on either lip reading or sign language or a combination of both. Children born deaf typically use primarily sign language (Kena et al., 2016).

In my professional experience during 13 years as the program specialist for this program, I was recognized by the state under study for having a model program for inclusion of deaf children into general education classrooms. I was fortunate to be afforded the opportunity to serve on the planning, building, and design of classrooms in a new school to accommodate children in need of assistance who were deaf and hearing impaired. Learning the technological advantages of the school pre-construction was invaluable. I was able to assure classrooms were compliant with sound dampening devices as well as amplification.

The school was a center school, a school where the majority of the community’s children needing assistance specifically related to hearing loss or were deaf attend. It was a difficult decision for the parents and district personnel to have children ride a bus longer than their neighborhood school bus to go to a different school due to a program they needed. The benefit overall was that they were able to communicate effectively with peers who were also deaf. This assisted students with social/emotional growth and well-being exponentially. The ability to meet the needs of children who were deaf in an environment where the teachers and administrators were culturally aware was also quite an advantage.
When a child is deaf, whether from birth or losing the ability to hear, they must be taught how to use an interpreter. Having children who were deaf on the same campus allowed the teachers of the students to understand the role and responsibilities of the interpreter. This was an important dynamic for all students to be able to learn. The program also allowed for multiple interpreters to be on the same campus and allowed flexibility in utilizing the interpreters.

**Hearing impairment.** The term hearing impairment refers to a hearing loss not covered by the definition of deafness. This type of loss can change over time. Under the federal guidelines, a student must have a deficit of 25 decibels plus or minus five decibels without hearing aids to be considered for the program (Kena et al., 2016).

Being hard of hearing is not the same thing as having trouble with auditory or language processing. The term hard of hearing means a deficit in the ability of the person to actually hear sounds. The inability to actually hear can be assisted through the use of hearing aids.

In my professional experience with this program, I noted the need for cultural understanding in the community. Hearing impairments could be mitigated through hearing aids or cochlear implants. There was a constant debate in the deaf/hard of hearing community about whether a child should or should not have assistance to hear. Due to this divided culture, educators had to tread very carefully when attempting to meet the educational needs of a child with a hearing impairment.

The principal requested that I observe a kindergarten child who was, in the opinion of the guidance counselor and classroom teacher, a selective mute. The teacher said he was extremely sweet and compliant; he just refused to talk. As I observed the
student in the classroom setting, he was attentive and worked well. Initially, I did not see an obvious issue that would perhaps keep him from wanting to talk. I did observe that he would work for a little while but kept looking ever so slightly to his left and right at his classmates, as if checking to see what they were doing. I noticed a slight delay in all transitions such as stopping one activity to transition to the next.

Throughout the school day, I observed him in many settings. In the cafeteria, he sat with classmates, not talking, just eating and smiling. At Physical Education, he would watch and then do the same as his peers. Walking from class to class, he followed in line like everyone else. The one thing he never did was he never attempted to ask a question or to speak at any time. This was a concern.

We asked his parent to meet to discuss her son to help us understand how he communicated at home. The parent shared he was one of eight children and was in the younger half of the siblings. She said he played with them, ate what he wanted, and was happy. When we asked her if he talked at home, she said she really had not noticed. We guided the parent to have his hearing checked, and she did so. He was diagnosed with a profound bilateral (both ears) hearing loss. He did not talk because he could not hear to learn how to make the sounds. In the end, he was fitted with hearing aids and grew his communication skills exponentially.

**Deaf blindness (Dual sensory impaired).** Children with a diagnosis of deaf blindness have both severe hearing and vision loss (Kena et al., 2016). Their communication and other needs are so unique that programs for just the deaf or blind cannot meet the severity of the need. Due to both senses being impaired, the student must have opportunities to access their education in every way imaginable such as auditory,
visual, and tactile. The reason for presenting material in all modalities is due to the potentially changing abilities of the child to see or hear even if the slightest amount.

In my professional experience, I had a student who presented primarily as deaf; however, her vision was so limited she had to be educated as though she were deaf-blind. The child entered school at the age of 4 as a child eligible for the program for the deaf. Her physician had presented a comprehensive audiogram showing her hearing loss for each ear, as well as her hearing ability with both ears. She had received a cochlear implant but did not like to wear it. As a pre-kindergarten student, to determine eligibility in the state under study, a physician’s report could be used as sole support to determine eligibility.

As the child began the school year, she was uncontrollable, physically. She often ran, fell, knocked over classmates, and bumped into adults. At first observation, she appeared to be uncomfortable in her new setting. We decided to work more one on one with her, so she could bond to an adult and potentially calm down. After approximately two weeks of this strategy, she had not calmed down much, but it did appear as though she was trying. The first epiphany was she did not know sign language. Her family had not learned any American sign language; therefore, their way to communicate with her for the first four years of life was to give her what she pointed at or what they thought she wanted or needed.

The second realization was that she was not intentionally running into people or things, but she did not actually see them. She tilted her head and held her chin up to see anything in her hand. It was as if there was a window in that exact spot that allowed her to see something. The data was collected and confirmed, and the parents were invited to
school for a meeting. We discussed our observations and findings and asked if her vision had been tested. The parents said there was no way to test her because she couldn’t communicate or sit for the test.

With the assistance of the school counselor, the family was able to get her to a specialist to have her vision tested. The child was diagnosed legally blind which changed our whole approach to teaching her. We then began using textures and rudimentary (beginner) sign language for all basic words such as bathroom, girl, boy, food, and drink. We made the conscious effort to talk and explain every little detail to her to establish sounds and communication and a tactile representation of the word/item. At the time of this study, the student was substantially behind her same age, same grade peers; however, she was growing academically and socially every day.

**Orthopedic impairment.** An orthopedic impairment is when children lack function or ability in their bodies that adversely affects their educational performance. These impairments include congenital anomalies such as absence of a limb or digit(s), clubfoot, bone tuberculosis, poliomyelitis, or amputations to name a few. Another example is a child born with cerebral palsy (Kena et al., 2016).

Several young men come to mind who were in this program during my tenure as a program specialist for this disability. I met one of them when he was in the third grade. He was not able to get up from a sitting position on the floor without assistance. He was an unstable walker in class and had to lean on desks for stability. There were times he used a walker to ambulate around campus. He used a wheelchair for long distances at times.
As the school year progressed, school personnel asked the parent to meet, so there could be discussions of concerns by school staff for her son’s independent functioning. The mother broke down in tears upon entering the room; she was distraught. She explained that her son had a terminal diagnosis of Duchenne Muscular Dystrophy. This disease is unforgiving, as it slowly takes away the child’s independence and they become wheelchair bound. The parent shared that, as a family, the decision was made not to tell her son he had the disease and that there was a wheelchair hidden at home for “when it happened.”

This young man was brilliant, made straight A’s, and was likable with a lot of friends. His mother was concerned that if he knew the extent of his disability he would be upset; however, he repeatedly asked her what was wrong with him. The parent was also concerned that the other students might treat her son differently. We told her they would treat him differently; they would want to do everything for him. Then the parent smiled and relaxed a little. Children are often accepting and nurturing in the young grades, and so the concern on our part was the child might develop learned helplessness due to too much help from other students. The parent began to realize her son was old enough now to learn has about his illness and disability. He was also old enough to begin counseling to understand it.

As time went on, he did end up in the wheelchair full time by middle school. This did not slow him down one bit. He was just as energetic, funny, and smart as always. In high school he was homecoming king and went on to college and graduated in 2018.
**Intellectual disability.** Children with this type of disability have below average intellectual ability. They may also have poor communication, self-care, and social skills. Down Syndrome is one example of an intellectual disability (Kena et al., 2016).

In working with children with intellectual disabilities, I had the opportunity to witness growth in ways many people do not understand. Children with intellectual disabilities do not learn in the same ways as their non-disabled peers. Their brain does not process information the same, and developmental milestones are not mastered in the traditional time frame. For example, as a baby, they may not roll over until they are two years old when a typically developing baby will roll over at about eight months of age.

Children who meet eligibility for the intellectual disability program are significantly below their same age peers in their ability to learn academic content. There was a student in the third grade who was struggling to read. He was unable to sound out words or blend letters, yet he had exemplary attendance and no history of any medical issues that would contribute to his difficulties. He did not follow class routines such as putting away his backpack each morning. When it came to math, he could not count past 20, and he could not isolate numbers.

This was a child who had been in school for three and a half years and had only grown to a middle kindergarten level in his academic ability. This was not due to a lack of exposure to curriculum, nor was it a medical condition. The parent signed consent for psychoeducational testing to provide the school information on how he processed information, as well as his memory ability, speaking ability, non-verbal ability, and Intelligence Quotient (IQ). This child was compliant, and his lack of abilities were not obvious to teachers until this point. His test results indicated an IQ in the low 60s which
meant he was eligible for an IEP. He was able to access his curriculum in a smaller setting allowing him to learn at his own rate and make progress. He may never perform on grade level; however, he was able to learn, just differently than his nondisabled peers.

**Traumatic brain injury.** This is a brain injury caused by an accident or some kind of physical force. A traumatic brain injury is a partial or total disability caused by injury to the central nervous system from physical trauma including anoxia. Head injury includes trauma to the scalp, the scull, and the brain. It can be a minor bump to the head (concussion) or a severe injury leading to coma (Kena et al., 2016).

In my professional experience, the most common causes I dealt with for traumatic brain injury were auto accidents, other four-wheel vehicle accidents, bicycle accidents, sports related head trauma, and anoxia. A young lady in kindergarten was determined eligible for this program. She was a victim of anoxia, or near drowning. She was with her family when no one noticed she had gone underwater and stopped breathing. The paramedics were able to revive her after several minutes of no oxygen getting to her brain (anoxia).

The parents brought her to school and were visibly afraid to leave her. They were guilt ridden and fearful for her safety every minute of every day. School personnel convinced them to leave her by explaining that we had two nurses on campus and explaining that she would be in a classroom with a lower teacher/pupil ratio and additional adult support for her needs. We were able to determine her eligible for the traumatic brain injury program and created an IEP to modify her curriculum and put accommodations in place for her to be successful in the school setting.
Her speech was very strained and at times unintelligible; therefore, she was placed in speech therapy. Her thought process was quite delayed, and she often lost her ability to respond to questions, so she received language therapy to assist her with this skill. She was not able to walk on her own, and she was in a wheelchair; therefore, she received physical therapy. She used assistive technology to help her respond using keyboarding and pointing to symbols as she lacked fine motor skills to hold a writing implement. She was a delightful young lady who brightened everyone’s day with her smile and had friends in every class.

**Multiple disabilities.** A child with multiple disabilities must have more than one condition covered by IDEA. Concomitant impairments, the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments (U.S. Department of Education, 2017). This term does not include students meeting eligibility for the Deaf Blindness program.

Many children have multiple disabilities that affect their ability to learn. When there are multiple areas of weakness, it is in the best interest of the child to be correctly identified by the programs for which they meet eligibility. There are various opinions about the need for this program, as some people feel one program identification is all a child needs to receive services under IDEA. While this thought is not wrong, it is not what is best to meet the specific needs of the student.

I received a phone call from the principal of a middle school on the first day of school. He had enrolled a sixth grade student who showed up with special needs. I went to the school immediately. When I first saw the student, he was walking with forearm
crutches, swinging them uncontrollably in the breezeway. I had never met this child previously, as he had just arrived from outside the school district in which I worked.

I asked the guidance counselor for his cumulative folder to see where he last attended school and what his needs were to access his curriculum and to be safe on campus. He had an IEP from out of our school district, and it identified his disability as Specific Learning Disability. While I did not doubt the due diligence of his previous school leaders in identifying him as such, I wondered why this was the only program for which he was identified. I contacted personnel at the child’s previous school, and they informed me of their position that the program did not matter, as long as he had an IEP. We immediately obtained consent from the parents to conduct a re-evaluation to determine him eligible for another program and provide physical therapy and occupational therapy which he needed and had not received previously.

**Judgments**

In reviewing my research questions, the following is my summation of each.

Research Question 1: To what extent is there a relationship between children born with a congenital heart defect (CHD) and being determined eligible for a program under the Individuals with Disabilities in Education Act (IDEA) criteria? It was apparent that children born with CHD were much more likely, 32% more likely, to be determined eligible for a program under the IDEA eligibility criteria.

Research Question 2: To what extent is there a relationship between how long a child has been under general anesthesia and being determined eligible for a program under IDEA criteria? As for the relationship of being under general anesthesia for an extended period of time and being determined eligible for a program under IDEA, there
was an obvious relationship demonstrated by the average number of hours each child in my study was under anesthesia. To be able to isolate each case was not possible based on parent reporting and not acquiring actual medical records. I also studied whether we could clearly state that the general anesthesia was the causal effect or whether the CHD was the main contributing factor for eligibility under IDEA. It was difficult to categorically state the CHD was the main contributing factor for eligibility due to the limited availability of information on children born with CHD. Based upon the literature I reviewed, the high relationship and in some cases correlation of anesthesia exposure and learning disabilities in general made it difficult to conclusively state that anesthesia was solely the cause or the CHD was the main contributing factor for eligibility under IDEA.

**Recommendations**

The health care system in the United States has been negligent in meeting the needs of all its citizens. Medical care has been based on socioeconomic status; the more money a person makes, the better health care they receive. This is probably not an epiphany or a surprise to many people living in the U.S.A. Due to this gap in medical coverage, we cannot truly obtain accurate data to assist in meeting the needs of our children in their educational setting.

Too many families are forced to prioritize food on their table over health coverage for their families. From the political spectrum, the concept of Universal Health Care could assist in closing the gap of medical coverage. Pediatric Cardiologists are not typically the physicians who patients will see in not for profit medical facilities. Without the experts in place to provide very necessary medical knowledge, children may not be properly diagnosed. This deficiency could lead to childhood mortality in children born
with CHD.

Until we have a policy in place which allows for educational professionals and medical professionals to communicate openly on behalf of children, educators are at the mercy of the parents for information. Parents have the option to report medical information or not per HIPPA. In my experience, many parents do not understand the medical terminology used by physicians to adequately relay medical information to the education professionals. Often, parents do not fully understand the potential educational struggles their child may face due to a medical condition. It is imperative a policy change within HIPPA is necessary to allow professionals to speak directly, to properly address the educational needs of children with medical conditions.

**Conclusion**

In conclusion, the data strongly supported the notion children who have undergone general anesthesia for a prolonged period of time prior to the age of 3 do have a greater risk of being identified as a child with a learning disability. Though one of my research questions caused me to probe whether it was exposure to anesthesia or the heart defect itself that caused learning disabilities, data are not fully conclusive. With the national average being 13% of the population found eligible for a program under IDEA, that was significantly below the 45% of children who had CHD and had undergone general anesthesia and were determined eligible for services under IDEA. The population of children who had been under anesthesia and had CHD whose parents I surveyed in this study did have a higher eligibility rate for IDEA than the rate of eligibility among the general population; however, there was not a significant statistical relationship based upon the data I identified.
CHAPTER FIVE

To-Be Framework

In my findings, it was quite apparent that the lack of prenatal medical care as well as early identification of congenital heart defects (CHD) in pre-natal and post-natal births was not consistent across cultures in the United States and abroad. For educators to have a more cohesive understanding and identification of children born with CHD, medical care in general must be broadened to cover all, not just those with insurance or money. When identification becomes more universal, it will be imperative that these children be tracked as they enter school to allow the educators the opportunity to learn about the children and how to best meet their needs academically.

Envisioning the Success To-Be

One of the biggest barriers to obtaining valid data on anything medical is the Health Insurance Portability and Accountability Act (HIPAA) of 1996 which is comprised of regulations protecting the privacy and security of certain health information (U.S. Government Legislation, 1996). A major goal of the security rule is to protect the privacy of individuals’ health information, called Protected Health Information (PHI). Embedded in this rule is also a subsection which states parents are not obligated to disclose their child’s medical information to anyone, including schools.

Context. The ultimate goal of this plan is to establish a position within every hospital pediatric cardiology unit that will employ an education professional. This person will be the expert in understanding not only education and special education law but will also have a global knowledge and perspective of medical conditions which could impact a child’s ability to learn. This person will have no less than a master’s degree in
education and a minimum of 15 years’ experience. His or her experience in teaching will be a combination of teaching children with and without disabilities. This person will also have a working knowledge of how specific medical conditions may impact a child’s ability to learn as well as strategies to assist the educational professionals in meeting the needs of the students.

In my experience, I noted there is a sense of guilt on the part of the parents of children born with medical conditions. Parents question what they could have done differently to keep their child from having a medical condition. In the cases of which I am aware, there was nothing that could have been done differently, the CHD was an anomaly. In my experience, typically there was not a genetic link to a family member; the child born with the CHD was the first in the family to ever have this diagnosis. As the child grew and did not meet expected developmental milestones, the parents began to question why not. Again, socially, there is a stigma to a child not being the same as their same age peers; therefore, parents do not often discuss this with their social group.

Through human nature, if there are siblings or casual friendships, parents and educators compare children. Parents compare everything from when the children began to walk to their ability to speak and ultimately, their academic abilities. It is imperative each child be understood for the individual they are with the abilities they have. In my vision for the future, assessment tools will be utilized to determine a baseline of abilities and then creating an individualized plan will be paramount to the success of children born with CHD. A common database to track the CHD children will allow for a much more expedient identification and intervention for the whole child.

A study conducted from 1997-2011 via National Health Interview Survey
questioned: What are the potential long-term outcomes in children aged 0-17 years with CHD? This study was a quantitative analysis of 420 children with reported CHD and 180,048 without CHD. The study showed there was a three times higher rate among CHD children in missing 10 or more school days per year (Razzaghi, et al., 2015). Such historical data should be available and utilized to move forward in assisting children with CHD. My study results concur with the data obtained from the National Health Interview Survey.

An analysis of more than 5,000 children born between 1976 and 1982 (Taylor, 2009) revealed the following information. All subjects were tracked from elementary through age 19 on their reading, writing, and math tests annually. Infants who had just one exposure to anesthesia showed greater risk of having learning difficulties than their peers with no exposure to anesthesia. Those with two or more exposures had a 60% increased chance of learning disabilities compared to those who had no surgeries. This historical data is further confirmation that there has been concern about children undergoing anesthesia and the potential negative outcome later in life.

As discussed earlier in my study, the inability to secure prenatal and postnatal health care is of grave concern in the world. The U.S. infant mortality rate has some association with and may be attributable in large part to disparities in socioeconomic status which in turn are associated with race and ethnicity. Considerable differences in socioeconomic status and resulting financial disempowerment may adversely affect food security and nutrition, education, and health care in local and regional communities. A comprehensive investigation and analysis of past trends of infant mortality is not only critical in developing effective public healthcare programs and policies, but also vital for
future health planning (He, Akil, Aker, Hwang, & Ahmad, 2015, pp. 4908-4920).
The purpose of learning and understanding history is so we do not repeat past errors as well as to grow and learn.

In the future, both medically and educationally, children with CHD will not be viewed any differently than their peers. In the medical culture, prenatal care will be equitable which will allow for early identification (in utero) of a fetus with CHD. With early detection, surgery can be performed either in utero or immediately upon birth to alleviate potential delays in treatment of the CHD. Educationally, a national database will be created and maintained from birth. The children born with CHD will be tracked for all developmental milestones. Early identification of deficiencies developmentally and implementing interventions with fidelity to mitigate potential delays later in life will be the keys to success for every child born with CHD.

With the implementation of a system from birth, specifically for the children born with CHD, there will be a seamless transition into public education. The areas of weakness will have already been identified and interventions will have been in place. The children will receive therapies as well as assessments of current cognitive abilities. This will transition to their public school services allowing them to continue to grow as they are able. Long term, the regression of skills will be negligible and growth imminent. Parents will not have to wait until their child fails to get their child the help they need to succeed. The stigma of the CHD will not be the pervasive issue, as the developmental and educational needs of the child will have been met for years; it will be the norm for the family.
**Culture.** It will be imperative that physicians and nurses work collaboratively with the education professional to connect with families as early as possible in the child’s life. There will be many early intervention programs available for families that can assist in a child’s educational journey. For example, in the state in which this study was conducted, there is a Diagnostic and Learning Service. This service assists in the early identification and services for children with disabilities at no cost to the families. This service is a direct bridge to the public education system in the state. This service will be more universally practiced and will be accomplished through networking with hospitals using the research contained in this dissertation as a base as well as studies referenced in this dissertation.

In the United States, there is a Federal Department of Education which mandates all children are entitled to a Free and Appropriate Public Education (FAPE). While the word “entitled” is written into the federal language, the understanding of this word varies based on various cultures and interpretation. Education is valued highly in our society, often as a social stigma or badge of honor. Those who struggle to learn and need additional support are often looked at differently by their peers. The goal of education is to become a fully funded initiative to meet the needs of our diverse learners.

In 1975, Congress promised to cover 40 percent of the average cost to educate a child with disabilities. Congress later amended the law to say that the federal government would pay a “maximum” of 40 percent of per-pupil costs. Today, the federal government pays less than half of what it originally promised in 1975. (National Council on Disability, 2018, p.1)
Due to the significant lack of funding, educators in public schools cannot meet the needs of students with disabilities effectively. There is a disconnect between what people perceive to be true and the actual truth. The federal government speaks as though the children with special needs generate more funding for public schools; therefore, their needs should be met. The reality is, yes, they do generate more funding than a child without disabilities; however, President Donald Trump proposed an education budget of $62 billion for the Education Department, a 12% decrease from what was enacted for 2019 (Friedman, 2019). It is apparent there is not a sense of need to educate all students with a proposed budget cut once again. Until the urgency is created to educate all children, those with disabilities will never have their needs met. My vision for the future includes such a sense of urgency.

School districts must also become culturally proficient in understanding the needs of their students. Lindsay, Robbins, and Terrell (1999) explained that “culturally proficient leaders display personal values and behaviors that enable them and others to engage in effective interactions among students, educators, and the community they serve” (p. 4). It is imperative communities embrace the differences and educate all children to the best of their ability. This may be difficult to do, yet far from impossible. The largest hurdle is the time and expertise to train those who teach all children.

With the creation and implementation of an education professional employed by the medical sector, a sense of urgency can be conveyed to change the course of education. Having a database maintained on a federal platform will provide necessary information to show the need for funding to be allocated from the federal government to the local education agencies. When information comes from the medical world, people
will listen, and there will be a different respect afforded the medical profession as a whole. It is this platform that is critical to the success of funding being secured to help students with disabilities.

**Conditions.** The Individuals with Disabilities Education Act (IDEA) requires public schools to provide *special education and related services* to eligible students, but not every child who struggles in school qualifies. To be covered, a child’s school performance must be “adversely affected” by a disability. It is imperative that a national database be created specifically for children born with CHD. This database will enable medical/educational professionals to track all children, their CHD, their eligibility for a program under the IDEA criteria and what their actual learning disability is. This database will be used to assist families and educators in meeting the needs of the children.

Each district within the state under study will employ a person with extensive knowledge of the local educational system as well as extensive knowledge in understanding IDEA. This person will understand in depth, the eligibility criteria for all programs under IDEA. This person will also be well versed and/or have the ability to learn about medical conditions and their potential impact on a child’s ability to learn. The funding for this position will come from the federal IDEA funds that each school district receives via state allocations. This will be an administrative position at the school district level that will also be responsible for overseeing eligibilities within the school district at the school level.

**Competencies.** The person in this administrative position who serves as the liaison between the medical sector and the educational sector will have to possess
outstanding communication skills and extensive knowledge of federal, state, and local laws. This person will also have to be extremely well versed in medical terminology and the potential educational relevance as it relates to various diagnoses. Professionals working to meet both sides of the child’s needs will have to come together to work for the child prior to the child failing in school. To accomplish this, the medical professionals who work with children with CHD will attend trainings conducted by the public education system in their home district. Conversely, the education professionals responsible for addressing the needs of the child will be invited to be taught by the medical professionals in understanding the varied diagnoses the children have and the potential challenges the children may have due to the diagnoses. This will be accomplished through an annual meeting to educate new educational professionals who will be responsible for educating the child with CHD.

When this vision is realized, children will receive the assistance they need to learn. The severity of the CHD will be correlated to potential learning challenges which will allow for a more proactive approach to educating our children born with CHD. From my experience, children with processing disorders are often viewed as willfully disobedient or unwilling to learn. With the highly qualified people in place from the medical world with a comprehensive understanding of the educational world and vice-versa, children will be set up for success without failing first. This is not a dream; it is a mission.

**Conclusion**

In a world where everyone is posturing to find fault, it is time to actively establish a solution. Creating a position in the medical world and a position in the educational
world that encompasses and embraces a child’s education is a major step forward. The following chapter outlines potential avenues to accomplish this vision.
CHAPTER SIX

Strategies and Actions

The most challenging area for educators and medical professionals is the effective sharing and understanding of information between the medical world and the educational world. The platforms upon which each operate are governed in opposite arenas meaning education is free for all, whereas medical assistance is governed by the ability to pay. Each school district must create an administrative position at the district level that will be responsible for identification and implementation of procedures and protocol for children who have a congenital heart defect (CHD) and have been determined eligible for a program under the IDEA criteria.

Strategies and Actions

There are several areas that need to be addressed. These include the lack of reporting of children born with CHD and the lack of follow up of those children born with CHD. Another area to address is eligibility of children born with CHD for a program under the Individuals with Disabilities in Education Act (IDEA).

Create a sense of urgency. I will schedule meetings with the Head Pediatric Cardiology Nurses at hospitals in my state to present my findings. I will incorporate into these meetings a comprehensive understanding of the eligibility requirements for programs under the IDEA criteria. Through this sharing of information, I will explain why it is imperative that the medical information about children born with CHD is important to have accessible through a database. This database must be updated in real time due to the many surgeries children with CHD undergo throughout their lives. The surgeries are often lengthy and require general anesthesia.
When the child is recovering from surgery, there is a neurocognitive delay in his or her ability to learn which must always be taken into consideration during the educational process. “Exposure to two anesthetics was associated with a 1.41% (95% CI, 0.50 to 2.31%) lower score in school grades and having three or more was associated with a 1.82% (95% CI, 0.15 to 3.49%) lower score” (Davidson & Sun, 2017, p. 844). The 95% is extremely high and it clearly shows that children who have undergone general anesthesia will have a difficult time returning to school and processing information which is important for educators to understand.

At the time of my study, there was not an initiative or professional organization that was tracking the educational needs of children born with CHD. Through my work with the American Heart Association, I will be able to create a state-of-the-art tracking program of children born with CHD and their eligibility for programs under IDEA. This will be a real time database that will allow hospitals to have access to enter the medical information. The educational information, such as present level of performance, will be entered into the database by me as the creator of this tracking program through exhaustive efforts with federal and state educational agencies. The initial data for children eligible for programs under IDEA will be obtained first through state reporting and then focused specifically on those with CHD.

The academic success rate among children with learning disabilities related to CHD will be reported on a bi-annual basis by each school district to the hospital-based administrator hired specifically for this position for updating the database. The information used for this database will be grade level equivalency exams at the local and state level. For children ages 3-5 who are evaluated and determined eligible for a
program under IDEA, this data will become their base line. As reported,

A quantitative analysis of four year old children was completed using the Peabody Picture Vocabulary Test (PPVT), the vocabulary portion of the Wechsler Preschool Primary Scales of Intelligence, and the picture vocabulary portion of the Stanford-Binet Intelligence Test. There was over a one standard deviation of the anesthesia exposed group and the unexposed group. The IQ scores on the PPVT were 17 points lower on the exposed group versus the unexposed group (Hollenbeck et al., 1986).

For grades kindergarten through grade 2 specifically, end of year local assessments will be utilized as well as any state generated assessments that may be given to track growth and mastery of grade level curriculum. For grades 3 through 12, state grade level equivalency assessments will be utilized to determine growth toward grade level proficiency and mastery of grade level curriculum as well as state generated alternative assessments when applicable. It is also acceptable to utilize psychoeducational testing to establish baseline abilities as well as to document growth when applicable.

**Develop the change vision.** A position at the hospital will be created requiring the following areas of expertise:

1. Master’s degree or higher, specifically in the field of education.
2. A minimum of 15 years’ experience in public education in a combination of classroom experience and leadership experience.
3. Extensive knowledge of federal and state laws pertaining to eligibility for students with special needs.
4. Comprehensive understanding of curriculum at every grade level.
5. Well versed in modifying curriculum to meet the needs of all diverse learners.
6. Moderately proficient in the use of technology and assistive technology.
7. Outstanding people skills in the ability to communicate effectively with and between doctors, parents and educators.

This person will be the primary contact in guiding the school system in bridging the gap between parents, teachers, and medical communities to provide the necessary services for a child to be successful academically in their least restrictive environment (LRE). A job description will be written and presented to the physicians outlining the aforementioned qualifications for the position. Once this is approved by the physicians, applications will be accepted. The applications will be filtered to omit those applicants who do not meet the qualifications outlined above. The applicant hired will work collaboratively and in the school district department of Students with Disabilities and with the director of the department to establish procedures to follow policies already established in identifying children with disabilities. From the time of identification for eligibility for a program under IDEA, all children will be tracked for their academic proficiency utilizing the student management system currently in place in the school district.

With the early identification of students with disabilities related to their CHD, these children will receive necessary supplemental services to achieve academically. The children will not fail before receiving the assistance they will need academically and/or behaviorally. With a pro-active approach to meeting the needs of the children with CHD, the learning gap that historically occurs while waiting for failure can be non-existent. Based on my experience, I have noted this gap never closes once it occurs due to the
increased rigor by grade level.

Through the utilization of the electronic student management system in the school district, the progress of the children will be monitored in real time. The progress reports, grades, and intervention data will be available to be viewed remotely which will allow for immediate adjustments to a child’s services should a decrease in performance be reported. This will be imperative for action to be taken quickly to mediate the potential cognitive stall that occurs with children who undergo anesthesia.

**Educate all parties.** Through the relationships built among the medical community and education professionals, the person in the position described above will coordinate bi-annual meetings with parents, physicians and educators to update educational information available as well as updates from the medical community. These meetings will focus on the importance of understanding the needs educationally and medically of children with CHD. The faster these needs are communicated across cultures, the better the outcome for the children to succeed academically. This will also allow open communication without violating any laws as they relate to HIPPA and confidentiality.

A database will be established through the use of the American Heart Association Heart Heroes survey to parents offering them the opportunity to participate. Parents of children with CHD will be invited to participate in this open forum framework. The physicians of the children with CHD will also be invited as well as all educators working directly with the children. This forum will provide open communication for all involved.

A database which includes academic growth as entered by the professional hired specifically to do so will be utilized on an annual basis to track growth. The information
will provide grade level equivalencies and documented growth in all academic areas. The database will be designed to create charts and graphs portraying growth or lack thereof based upon data entered from district and state assessment scores.

**Conclusion**

As the actions necessary to move forward on behalf of all children born with CHD may appear daunting, they are completely within reach. Connecting with key people in the medical and educational arenas will take preparation and time. Once these connections are made, it will be imperative to educate all parties on the current policies and address needed revisions to policies on behalf of the children.
CHAPTER SEVEN

Implications and Policy Recommendations

It is imperative that hospitals establish a position to implement policy and procedures in meeting the educational needs of children with CHD and those who were under multiple general anesthesia surgeries. The needs of these children are not being met until they fail in the academic arena. This under identification or delayed identification creates a learning gap that is not easily, or in some cases ever, closed. This places the children at a deficit in successfully transitioning from grade to grade throughout their academic careers.

Policy Statement

This policy is directly related to the data reported in my study of children born with CHD. According to Kena et al. (2016), the average number of hours a child born with CHD is under general anesthesia prior to the age of 3 is 22.44 hours. Of these children, 43% have been determined eligible for services under the Individuals with Disabilities in Education Act (IDEA). In 2013-14, the number of children and youth ages 3-21 receiving special education services was 6.5 million, or about 13% of all public-school students. Thus, the population of children with CHD who have undergone general anesthesia that were identified as eligible for services under IDEA was markedly higher than children in the general population.

In more than 30 years as a public-school teacher and district level administrator, I have had first-hand experience in working with children with special needs. I have also served as the American Heart Association Heart Heroes education expert for 19 years. My professional experience led me to research the laws related to children with special
needs as well as learn the medical implications of all conditions and how they may relate to learning challenges. Being at the district level working with parents and educators, the need is extensive for the medical community to embrace the educational challenges of the children with CHD and work together for the children. My experiences in both sectors is what led me to this research and fueled my passion for the topic.

Through the implementation of an education expert position in the medical sector, children will have their educational needs met much younger than previously. With intensive support from the earliest age possible, children will have a greater opportunity to reach their developmental milestones the same as their non-disabled peers. Skills such as taking a first step, smiling for the first time, and waving “bye, bye,” are called developmental milestones. Children reach milestones in how they play, learn, speak, act, and move (crawling, walking, etc.) (Centers for Disease Control, CDC, 2019). CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD) is committed to helping children with developmental disabilities and their families get the support they need to thrive.

**Analysis of Needs**

There are six areas of need that must be addressed: Education, Economic, Social, Political, Legal, and Moral and Ethical. All of these areas are analyzed for their potential impact on the life a child. Scholarly research was conducted to assist in a comprehensive understanding in each area.
**Educational analysis.** Students with disabilities are lagging behind their able-bodied peers when it comes to high school graduation. “As the U.S. is on track to reach 90 percent graduation rates by 2020, students with disabilities only graduate at a rate of 61.9 percent” (America’s Promise, 2015). According to the America’s Promise Alliance 2015 report, Building a Grad Nation, this is the documented reality of children with disabilities. If we can identify these children earlier in their life, we can mitigate the deficit and increase their academic success, and in turn, increase their graduation rate.

The early identification of students with disabilities is accomplished through Response to Intervention (RTI) (Appendix C). “RTI is a process that highlights how well students respond to changes in instruction in the classroom. Individual students’ progress is monitored, and results are used to make decisions about future instruction and intervention” (AUSPELD, 2019).

Today, there are nearly 1.5 million infants, toddlers and preschoolers with disabilities (U.S. Department of Education, 2015) receiving early intervention and/or preschool education and 6.6 million children with disabilities attending the nation’s K-12 public schools (Kena et al., 2016). States embraced both research and best practice that show children who need early intervention and support will have better long-term academic, social and emotional outcomes if they are identified and served early.

The sooner this model is implemented, and identification is made, the quicker a child receives necessary accommodations and modifications to be successful academically. This keeps a child from experiencing learning gaps, achievement gaps, or opportunity gaps which allows them to master grade level expectations. Generally, learning gap refers to the relative performance of individual students – such as the
disparity between what a student actually learned and what he or she was expected to learn at a particular age or grade level. An opportunity gap refers to inputs – the unequal or inequitable distribution of resources and opportunities. Achievement gap refers to outputs – the unequal or inequitable distribution of educational results and benefits (Partnership, 2013).

**Economic analysis.** Based on data from the Census Bureau’s Current Population Survey (CPS), the 2017 dropout rate for 15-24-year-olds with disabilities (6.2%) was not measurably different from the rate for their peers without disabilities (4.6%). “While students with disabilities have shown some progress, with 65.5 percent now graduating on time, they still lag almost 19 percentage points behind the national graduation rate” (U.S. Department of Education, 2017, p. 1). Median weekly earnings of full-time wage and salary workers age 25 and older were $909 in the second quarter of 2017. Full-time workers without a high school diploma had median weekly earnings of $515, compared with $718 for high school graduates (no college) and $1,189 for those with a bachelor's degree. Full-time workers with advanced degrees (professional or master's degree and above) had median weekly earnings of $1,451 (U.S. Bureau of Labor Statistics, 2017).

Clearly there is an identifiable disadvantage for children with disabilities to succeed later in life. Taking into consideration the educational challenges children with CHD encounter and the statistics available, there is an urgent need for the policy presented. The economic impact for those with disabilities is documented and must be addressed as early as possible in the child’s life.
**Social analysis.** Many children from birth undergo surgery for their CHD. With this surgery, there is typically a scar left for life down the middle of their chest. This scar can become a badge of honor, or in teen years, an embarrassment for peers to see. With early education and a comprehensive understanding for the families, the educational supports a child needs can be determined early on through acceptance and understanding.

My study shows 43% of the children born with CHD were determined eligible for a program for students with disabilities. For those students determined eligible for an Individualized Education Plan (IEP), some were determined prior to school age; however, most, were determined once they entered school. The unfortunate truth is most had to fail in school to be considered for the IEP. There is a social stigma for the student and the family when a child is in need of Exceptional Student Education (ESE). In my experience as an educator, I witnessed many distraught parents attempting to understand why their child was struggling and what it would mean if they were enrolled in an ESE program.

In the state in which this study was conducted, the following statutes were in place:

Any student in kindergarten through grade 3 who exhibits a substantial deficiency in reading based upon screening, diagnostic, progress monitoring, or assessment data; statewide assessments; or teacher observations must be provided intensive, explicit, systematic, and multisensory reading interventions immediately following the identification of the reading deficiency. (Citation withheld to protect confidentiality)
A school may not wait for a student to receive a failing grade at the end of a grading period to identify the student as having a substantial reading deficiency and initiate intensive reading interventions, per state statute in the state under study. To be promoted to grade 4, a student must score a level 2 or higher on the statewide standards assessment in English Language Arts required for all students in grade 3 across the state under study. If a student’s reading deficiency is not remedied by the end of grade 3, as demonstrated by scoring Level 2 or higher on the statewide standards assessment required for grade 3, the student must be retained (Citation withheld to protect confidentiality).

The intent of the statutes is often misunderstood. The families of children born with CHD struggle to have school personnel understand their child’s disability. Children born with CHD often look, walk, and talk like their same age, same grade peers; however, their ability to process information is not the same. It is for this reason, despite the good intentions of the authors of statutes, some children will simply not be able to meet the standard at the time they are expected to do so. This leads to the social stigma of retention at age 8 and 9. This can be devastating to the child and the family.

**Political analysis.** The President’s Fiscal Year 2019 Budget provided $63.2 billion in discretionary funding, a $3.6 billion or 5% decrease below the 2017 enacted level. The 2020 budget requested $62 billion for the Education Department, a 12% decrease from what was enacted for 2019 (U.S. Department of Education, 2020).

When Congress signed what is now the Individuals with Disabilities Education Act (IDEA) into law in 1975, they acknowledged the fact that too many children with disabilities were either receiving a substandard education or were not attending school at all. The then-new law made a promise that every eligible child with a disability could go
to school and be provided with the individualized special education and related services necessary to learn and make progress alongside their brothers, sisters and neighbors. The law stated the opportunity to accept federal funding to provide a free, appropriate public education in the least restrictive environment to eligible children with disabilities.

Congress committed to providing states funding up to 40% of the average per pupil expenditure; to help offset the cost of educating children with disabilities. In the 43 years since the law’s passage, Congress has never lived up to that funding promise and schools have had to rely on local and state dollars to make up the shortfall. At the time of my study, Congress was only paying 16% of special education costs (National Council on Disability, n.d.).

The historical trend is not looking any brighter. With the current political state and impending budget cuts, there does not appear to be a legitimate solution or proposal to meet the needs of children with disabilities. The burden to provide the much-needed services to students with disabilities falls on the local education agency. The funding does not increase, yet the needs of the children increase.

**Legal analysis.** The Health Insurance Portability and Accountability Act of 1996 (U.S. Government Legislation, 1996) was enacted by the United States Congress and signed by President Bill Clinton in 1996. HIPAA restricts access to individuals' private medical information. A HIPAA violation occurs when a person or organization that has confidential patient information discloses it to a third party without the authorization of that patient.

Without divulging protected information or specifics about a medical condition, it is in the best interest of the child to share with educators if there is a medical condition
that may contribute to a child’s ability to learn, so the school personnel can meet the child’s needs without delay. In the public school system of the state under study, a child must show a significant delay in their ability to learn to be considered for academic assistance. When there is an underlying medical condition that has not been shared, the lack of information delays the identification process.

The inability for school personnel to access medical information is to the detriment of the child. Having a person employed in the medical sector who understands the education sector is imperative to communication on behalf of the child. This person will have the ability to obtain consent immediately for open communication between the two agencies to work quickly and effectively on behalf of the child.

**Moral and ethical analysis.** Public school educators in the state under study agree to the code of ethics of the education profession that states,

> The educator values the worth and dignity of every person, the pursuit of truth, devotion to excellence, acquisition of knowledge, and the nurture of democratic citizenship. Essential to the achievement of these standards are the freedom to learn and to teach and the guarantee of equal opportunity for all. (Citation withheld to protect confidentiality)

Equal opportunity for all is the most difficult to accomplish as funding for students with special needs is not available to do so. While students attend school every day, this does not infer that all children are given equal access to their education for the varying needs of the children.

Merriam Webster defined the word moral as, “of or relating to principles of right and wrong in behavior” (Moral, n.d.). Morally, we have an obligation to do what is in
the best interest of the children; however, the systems put in place by the federal
government and local education agencies tie the hands of the educators to act swiftly.
Morally and professionally, we know what needs to be done for our struggling
students; however, procedure and protocol delay the educator’s ability to modify,
adapt, and accommodate curriculum.

Implications for Staff and Community Relationships

There are potential positive and negative implications in a position created to
bridge the medical and educational communities. A potential positive implication is that
the verbiage used in both sectors will be understood in more depth by both parties. By
speaking the same language, the correct questions will be asked yielding a streamlined
response specific for the area of concern. This will eliminate waiting for pertinent
information to be disseminated between the two disciplines to move forward on behalf of
the child. A potential negative implication is one of the two sectors believing they do not
have to provide information in the best interest of the child. With HIPAA being the
governing law ensuring confidentiality of medical information, there will have to be an
understanding of the importance of sharing medical information with the education
professionals.

This is an opportunity for communities to work together for the child. The early
identification and intervention for children with CHD is imperative in keeping the
learning gap from growing prior to school age. When a child displays a delay
developmentally, it is in the best interest of the child to receive therapies as young as
possible. As stated earlier, “Today, there are nearly 1.5 million infants, toddlers and
preschoolers with disabilities receiving early intervention and/or preschool education” (U.S. Department of Education, 2016).

In my professional experience, I have noticed there is a sense of strength that happens when both parties speak the same language. When sitting at the table, discussing the child, having a person who understands both the medical and education relationships helps put the parent at ease. In such meetings, I concentrate on not speaking in acronyms or using uncommon terms. The ability to assist families and bridge the gap between school supports, therapeutic supports, and medical supports, creates a sense of calm among the stakeholders. Everyone walks away from the table feeling as though they have been understood and that everything possible is being done for the child.

Establishing stakeholder relationships builds the strength of the community in many ways. In my experience, the person making the medical-educational connections for families and all stakeholders becomes the “go to” for any and all questions related to the educational needs of children with CHD. The person in this role has the ability to not only answer questions but to seek solutions for those needing assistance. Due to this ability, the relationships for all parties in the community are strengthened.

**Conclusion**

Creating a position within the medical world that focuses on the education of children born with CHD is assigning a sense of urgency to the nature and severity of the academic concerns for the children. The early identification for those children who struggle academically is imperative to the children’s success in their future education endeavors. There is a far and long reaching implication if the educational needs are not
met early from dropout rate to lack of potential earnings throughout the person’s life. The return on investment of creating the position of a medical-educational expert liaison will be seen as early as the retention rates in elementary school decrease due to the early identification of children with disabilities.
CHAPTER EIGHT

Conclusion

I conducted this study due to my personal experiences, my professional experiences in Exceptional Student Education, and my involvement as the education expert in the American Heart Association Heart Heroes. Having the opportunity to assist families of children with CHD, I realized there was a need for this study. The data gathered will give current as well as future families with children who have CHD information that will assist them in advocating for their children to receive the assistance they need to learn. Showing the relationship to the eligibility in receiving services under IDEA and the exposure to general anesthesia will assist educators in understanding the unseen disabilities. Creating a position within the medical field to navigate the education world will expedite services families can access prior to a child being school age. This is an urgent bridge to build for the success of all children born with CHD.

Discussion

The purpose of this study was to draw awareness with research supported data to validate the diverse learning needs of children born with CHD. Based on more than 30 years of experience, I realized the educational community at large often chooses a path of negativity and resistance to understanding the medical implications on the learning and behavioral concerns of children born with CHD. When a study is able to determine a significant relationship between a medical condition and learning needs, the educational world listens. It is time for there to be a document to assist all stakeholders in understanding our diverse children’s needs.
The survey process I used, allowed me to obtain information directly from the families of children born with CHD. I was able to use the surveys completed by parents to secure the medical information I needed without violating HIPAA laws.

My goals were addressed through disaggregation of data. I was able to determine such relationships among children born with CHD, general anesthesia, and eligibility for a program under the IDEA criteria. While the data collected shows a higher eligibility rate for children born with CHD under IDEA than the general population, there is much work to be done to bring this number down. The early identification of developmental delays prior to school age is imperative to closing the learning gap.

In order to address my goals, I provided the results of my study to the American Heart Association Heart Heroes organization. Families of children with CHD will have access to the results allowing them to have research specific to their children’s potential struggles academically. This is only the first step in achieving my goals. The next step is meeting with pediatric cardiologists to discuss my findings and advocate for an education expert position within their practice.

The part of the organizational change plan that will be a challenge is creating a proposal that will allow me to secure a meeting to present my findings and advocate for a position in the medical sector. There is an unspoken tension between education and medical professionals as to who understands children best. Medical professionals know the medical side and what can be anticipated physically among children with CHD. The education professionals work with the day to day needs of each child who enters the school. The challenge is to get the two stakeholder groups to work together for the success of the child.
By creating the education professional position within the medical world, the sharing of pertinent information between the two parties will be expedited. There will be minimal delays in acquiring information which will allow decisions to be made for children with CHD in a much timelier manner than waiting for children to struggle or ultimately fail. The educational professional in the medical world will also assist families in bringing their concerns to their physicians and getting help immediately by having a knowledgeable and trusted individual right there to bridge the medical community and the local education agency. For many parents, navigating the school system is a foreign concept and intimidating endeavor. The educational professional in the medical world, who may be called the Administrator of Educational & Medical Information, will alleviate a lot of anxiety for parents as they realize their child is receiving the assistance he or she needs to succeed academically.

**Leadership Lessons**

The greatest leadership lesson I have learned from this process is the need to listen and learn. It is imperative there is not a preconceived idea of what I think should be done to help children struggling in school. I will consider information presented to me and study data looking for strengths and weaknesses and how they may be related to the child’s medical condition. I must find as much information as I can, both medically and academically, and relate everything to my passion for children. In everything I do, I picture a child, a child expecting me to be there for them, to be able to see their potential and help them achieve through adapting and modifying their curriculum for success. As a leader, I must always think ahead about potential barriers and solutions for the teacher and child with anyone with whom I am speaking. I cannot wait, I must create the
Administrator of Educational & Medical Information position and implement it with intent, passion, and desire to help all those children I can to be successful in their educational journey.

I will use my last four years acquiring my Education Doctorate to pursue creating educational expert positions within pediatric cardiology practices. I will first approach pediatric cardiologists who are currently known to me and share my concept with them. I will use my expertise from my study to explain why there is such an urgency to implementing this position. I will then reach out to those with whom I have worked in the education sector to recruit individuals who can fulfil the demands of the position.

Conclusion

Through this process, I relived my experiences of more than 30 years in education. I am perpetually struggling to reach and assist as many children as possible in their educational journey. I am often frustrated when I hear of a family struggling to get their child the help they so desperately need. I want to help as many children as I can to be successful academically with as few tears and as little frustration as possible. I actually hated school growing up. I didn’t get it. It was foreign to me. I did not learn like any others in my class. I was so fortunate to live in a small town where people showed love and patience and perseverance in my educational journey. “Be who you needed when you were younger” is tattooed on my arm for this exact reason. I will be there for all children who need me.
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Appendices

Appendix A. Parent Survey
Appendix B. Strategies and Actions
Appendix C. Response to Intervention (RTI)
Appendix D. As Is / To Be
Appendix A

Parent Survey

Lorilynn V. Bowie

Ed.D. Dissertation Data

This information is being used for data gathering purposes only. No identifiable information will be published or shared at any time. If you would like the results of this study, please provide your email information, results will be sent electronically.

_____ Yes, I give permission to use information I provide for your study.

**Optional Information** (you are not required to give this)

Parent(s) Name(s) __________________________________________________________

Contact Phone ____________________________________________________________

Contact Email ____________________________________________________________

**Required/Requested Information** for data gathering purposes ONLY.

Today’s Date: ___________________________________________________________________

How old is your child currently?

____________________________________________________________________________

What age was your child diagnosed with a Congenital Heart Defect (CHD)?

_________

What is your child’s CHD?

____________________________________________________________________________
How old was your child when they had their first surgery?
________________________

How many surgeries has your child undergone to date?
______________________________________________

To the best of your recollection, how many total hours has your child been under general anesthesia?
_______________________________________________________________

Does your child have an IEP? If yes, please circle the program(s) they are receiving services for:
Other Health Impaired (OHI), Specific Learning Disability (SLD), Language Impaired (LI), Speech Impaired (SI), Autism Spectrum Disorder (ASD), Emotional Behavioral Disorder (EBD), Other ______________________.

How long has your child had an IEP?
_______________________________________

Does your child have a Section 504 plan? __________ YES
## Appendix B

### Strategies and Actions

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Create a Sense of Urgency</td>
<td>• Conduct a meeting with the Pediatric Cardiology physicians at their hospitals to discuss the importance of understanding the CHD and the impact anesthesia has on a child’s ability to learn.</td>
</tr>
<tr>
<td></td>
<td>• Utilizing data available, show the disparity among those children who have undergone anesthesia and their eligibility for a program under IDEA versus those children who have not.</td>
</tr>
<tr>
<td></td>
<td>• Create a national database of children born with CHD to allow tracking of surgeries as well as eligibility and academic needs/deficiencies.</td>
</tr>
<tr>
<td></td>
<td>• Use the information available to advocate for children on a case by case basis to assist in receiving the support they need to achieve academically and behaviorally.</td>
</tr>
<tr>
<td>Develop the Change Vision</td>
<td>• The physicians and the parents involved will discuss the specific medical needs of the child and create a plan to address their needs both medically and academically. This will be done with the physicians and education expert.</td>
</tr>
<tr>
<td></td>
<td>• This vision will then be taken to the home school district and a plan will be implemented for the child immediately.</td>
</tr>
<tr>
<td></td>
<td>• Short term objectives as well as long term goals will be clearly stated and addressed for daily accessibility as well as all testing situations.</td>
</tr>
</tbody>
</table>
| Educate all parties | • Educate medical professionals about the various programs for which a child can be determined eligible under IDEA.  
• Educate the parents about their child’s medical condition and how it may impact them in accessing their education.  
• Work collaboratively to meet the needs of all children born with CHD. |
Appendix C

Response to Intervention (RTI)

I think that there is a problem with my child's reading/spelling/writing/maths even though other areas of their development, including language, appear to be age-appropriate.

- **YES**
  - Make a time to raise your concern with your child's teacher.
  - Are you still concerned?

  - **YES**
    - Ask the teacher to outline the type of assistance that is being provided in the classroom and the strategies that are being used to target any areas of concern.
    - Are you still concerned?

  - **NO**
    - I am satisfied with my child's progress and the steps being taken to address any areas of concern.

- **NO**
  - Ask if your child could be given the opportunity to participate in a small group Intervention targeting his/her specific areas of weakness. It will be important that any Intervention program is delivered explicitly, over an extended period of time and that your child's progress is monitored carefully.
  - If the school does not have the resources to provide this, it may be necessary to find a similar type of support out of school.
  - Are you still concerned?

- **YES**
  - If your child has received at least six months of ongoing and consistent small group or one-to-one support and you are still concerned about their progress, an assessment of their cognitive processing as well as their learning strengths and weaknesses should be completed by a qualified professional.
  - Your child is also likely to require ongoing individualised instruction using a structured, systematic program and the provision of classroom based accommodations to support their learning.
  - Are you still concerned?

  - **YES**
    - Additional support is recommended through the use of a specialist tutor who is able to provide additional evidence-based, systematic intervention that targets your child's specific areas of weakness.
    - Ongoing monitoring of your child's progress is essential.
Appendix D

As Is / To Be

“As Is” C’s Analysis for CHD, Anesthesia, and IDEA eligibility—L.V. Bowie

Context
- Lack of reporting follow-up of children born with CHD being determined eligible for a program
- Out of children reported as being born with CHD

Conditions
- Age of identification
- Parental understanding of child’s needs
- Available resources for parents pre-school age and school age

Culture
- Child had surgery, they are “cured”
- First child of family no knowledge of developmental milestones
- Child is born with life threatening condition – they are going to die any day

Relationship of: Identification of learning disabilities due to exposure to anesthesia as an infant when diagnosed with CHD

Competencies
- Understanding of CHD severity
- Knowledge of ESE eligibility
- Limited knowledge of anesthesia & effects
“To be” 4 C’s Analysis for CHD, Anesthesia, and IDEA eligibility— L.V. Bowie

Context
- Develop a follow-up reporting system of learning/academic abilities
- Create a position in a hospital for an education expert/advocate

Culture
- Parents are educated in basic terms about their child’s CHD & treatment
- Realistic data is shared with parents of potential programs under ESE

Conditions
- Create information specific for parents of children born with CHD & how it can impact learning
- Electronic database created to track children with CHD

Competencies
- Severity of CHD is correlated to potential challenges learning
- Comprehensive understanding of ESE & eligibility and resources available

Relationship of:
Identification of learning disabilities due to exposure to anesthesia as an infant when diagnosed with CHD