

**MEETING THE NEEDS OF MEDICALLY FRAGILE/CHRONICALLY ILL  
STUDENTS: THROUGH THE LENS OF URBAN SCHOOL  
ADMINISTRATORS**

A Dissertation by

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## **ABSTRACT**

The purpose of this study is to examine the perceptions of four urban administrators and their management of students with chronic health conditions in the school setting. Generally speaking, there exist a scarcity within the literature that emphasizes leadership practices specifically related to serving students with chronic health conditions in the school environment. As such, the voices of school administrators and their direct and indirect influence on managing the school experience of these students is essentially non-existent.

This study advances an illustration of how school administrators describe their personal characteristics in the management of students with chronic conditions; how they exercise and interpret their acts in the management process; and how administrators describe their leadership acts related to both the academic achievement and social adjustment of students with chronic conditions in urban school environments. Findings from the study reveal that school administrators recognize that their involvement in managing a caring culture for students with chronic conditions is paramount for both their academic and social success; and they believe that they embody the leadership characteristics conducive to establishing a thriving culture for students.

Additionally, new findings reveal that though school leaders are engaged, they lack a uniform process in managing students with chronic conditions. Their voices also developed a Multicultural Critical Care leadership model that integrates the imperativeness of leading with a moral compass, creating inclusive environments and relying on transformational leadership practices in this critical process.

## DEDICATION

“For I know the plans I have for you”, declares the Lord, “plans to prosper you, plans to give you a hope and a future” –Jeremiah 29:11. This work is the absolute representation of answered prayers and evidence of a journey perfected by divine guidance.

This study is dedicated to my father...my dad the late Henry L. Harrison. You set a standard that I didn't always comprehend but it was one deeply rooted in your understanding of the power of education. Not until your passing did I fully appreciate your legacy but I am so grateful that you gave me everything I needed to get to this point. May this work be your voice and the stories you wanted to tell. May it be evidence of your brilliance and the source of a legacy continued.

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To my nieces and nephews, may these pages inspire you to live beyond your potential.

To my family, friends and the KEEY community, let this work fuel your passions.

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All work for the dissertation was completed by the student, under the advisement of Professor Norvella Carter of the Teaching Learning and Culture Department and Idethia Harvey of the Department of Health and Kinesiology.

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## **CHAPTER I**

### **INTRODUCTION**

Perrin, Bloom and Gortmaker (2007) asserts that over the past 4 decades youth have been diagnosed with chronic illnesses at a significantly higher rate. Essentially, it is further estimated that these illnesses, which are not necessarily terminal, impacts 20% of school age children (Harris, 2009; Sexson & Swain, 1995). As a result of frequent absenteeism, individuals with chronic illnesses may experience academic failure, psychological implications, school withdrawal and other social issues (Sexson & Swain, 1995). This causes significant concern amongst educational practitioners and calls attention toward the educational implications for these chronically diagnosed patients.

Due to advances in treatment, the number of children returning to school with chronic illnesses is increasing (Sexson & Swain, 1995). Yet, additional problems ensue, as studies have shown that school personnel have little knowledge about chronic illnesses and feel unprepared to deal with these students in the classroom (Kilebenstein & Broome, 2000). The school reintegration process for students returning to school following the treatment of a chronic illness can induce devastating social and academic struggles (Prevatt, Heffar and Lowe, 2000). Students may struggle with learning disabilities secondary to treatment, anxiety surrounding physical changes, and peer challenges upon their return to campus (Prevatt, Heffar and Lowe, 200). Therefore, the process by which schools and their leaders practice or manage the care and education of these students is extraordinarily important.

Without a comprehensive plan, resources and training, school leaders may also face unwelcomed procedural and legal mishaps regarding the proper and appropriate servicing of students with chronic illnesses. Limited research explores the perceptions of administrators regarding this process and their role in the formation of a solid school management program within schools. Moreover, considering the advent of health disparities among youth in urban communities, and the significant academic, racial and economic inequities that typically exist within these schools, the educational implications for urban students with chronic illnesses evokes a more complex level of concern for school administrators and personnel (Fiscella & Williams, 2004).

When lingering and common implications evolve as a result of chronic illnesses intersect with pre-existing factors within urban communities, it should come as no surprise that such crossroads may lend itself to significant educational challenges for urban administrators. Yet, limited but evolving research exists to serve as an appropriate tool when exploring the educational management and school reintegration process for students with chronic illnesses in general. However, the implications of challenging social- structures that have historically stifled African Americans, Latino and low income populations in urban communities certainly intensifies when chronic illnesses occur.

Extensive research offers concerning confirmation that youth within urban communities are commonly products of environmental toxicities which challenges their health and cognitive functioning (Cappella, Frazier, Atkins, Schoenwald and Glisson, 2008). Researchers have explored poverty stricken youth within urban communities who

are known to suffer from attention deficit, asthma, lead poisoning and ongoing health conditions that cause implicit concern for leaders within schools (Currie, 2005). The implications are drastic for students of low socioeconomic status, as it worsens their educational achievement, occupation choices and income. The long-term ramifications for students deserving of an impeccable future can ultimately illustrates the generational burdens of residential segregation (Fiscella and Williams, 2004). These consequences continue to have unprecedented implications for school leaders.

Though these concerns for urban communities are deeply rooted in the historical fiber of our American culture, the lingering implications for students with chronic health conditions are magnified given mandates highly influenced by increasing accountability and sweeping political bantering. These rampant mandates should serve as a consistent reminder that educating all students is imperative, but particular interest toward specialized populations impacted by pervasive racial and health disparities is vital. It is increasingly advantageous for administrators, educational leaders, policy makers and medical professionals to evaluate the systematic processes by which we simultaneously manage the educational and social needs of chronically ill students. In doing so, all stakeholders can ascertain that schools in urban communities are not only achieving the mandates of local, state and national mandates but are offering appropriate educational opportunities for ALL students including those living with a chronic diagnosis. This research will focus intently among the drivers of the school...educational leaders.

## **Theoretical Framework**

### ***Ethics of Care***

Significant research capitalizes on a feminine approach to meeting the unique needs of all students. Nel Noddings continues to serve as a catalyst toward a theoretical framework for imposing an ethics of care in the educational management of students across the country. As one of the forerunners of care-related theory, Noddings asserts that needs-based emphasis is a foundational premise (Noddings, 2005; Burke, Nolan & Rheingold, 2012). School leaders play an irrevocable role in maintaining an imperative focus on the diverse and sometimes challenging needs of urban students; specifically those with medical or special needs.

Charged with the long term academic and social success of all students, including those with medical needs, leaders must cultivate a culture that supports the success of its students well beyond their present academic experience. Noddings' (2005), contends that the ethics of care is a future-oriented model that requires leaders to make decisions that will benefit the whole-child not only in the present but in the future as well. In regards to meeting the varied needs of urban students with chronic illnesses, Noddings confirms that "overwhelming needs cannot be met by the usual process of schooling" (Noddings, 2005). She further recognizes that leaders within poor communities are often expected to provide full service options to students and families who are unable to access medical and social services (Noddings, 2005).

Nel Noddings' Care Theory is also generally regarded for its emphasis on attention and motivational displacement. It is characterized by caring persons, or in the case of this research the school leader being consistently present in the process of creating systems, developing a culture and managing the academic experience of

chronically ill students in urban communities (Burke, Nolan and Rheingold, 2012). Further, it has the potential to delineate avenues by which school leaders are readily available to intently recognize the needs of their students, a process known as engrossment (Burke, Nolan and Rheingold, 2012). More specifically, Noddings' (2005) describes motivational displacement as channeling ones motivational energy toward servicing all students with specialized needs of urban students.

Generally speaking, enduring, reciprocal and responsive relationships serve as solid tenets of the care ethic (Rabin, 2012). Given the racial and cultural differences that impede the educational processes of urban schools across the country, the care theory offers a necessary framework for leaders charged with planning for students with significant needs (Vikan, Camino, Biaggio, 2005).

### ***Multicultural Ethics of Care***

In Valeria O' Pang's efforts to initiate changes in schools, she presents in her Multicultural Caring Centered Model that schools are models of social systems that should fundamentally embrace compassion and social justice (Pang, 2005). Like Nel Nodding, her work encourages the development of communities rooted in care (Pang, 2005). Evaluating this added perspective to the ethics of care framework is paramount given the popularized attention toward building the critical consciousness of urban school leaders to address academic and psychosocial needs of students. Urban school leaders must acknowledge and account for the students' diverse language, social, ethnic and economic backgrounds of all students. These differences are often exacerbated when

urban health challenges are prevalent. As such, leaders must ascertain that a formidable integration of values, behaviors and routines are embedded in a community culture of high academic achievement within all students from all backgrounds despite any medical conditions (Pang, Rivera and Mora, 1999). To that end, O’Pang in her most recent work, underscores a disconnection between teacher preparation programs and the teachers’ efficacy with providing equitable opportunities in education. Though O’Pang and other researchers acknowledge the increasing need to enhance the credibility of multicultural relevance in teacher education, her evaluation of multicultural teacher education as a cross disciplinary field purports the necessity of focused leadership.

Essentially, this study evaluates through the eyes of educational leaders the colliding infrastructures of two social institutions, education and health care, that so deeply impact the futures and experiences of students across the globe. Leaders charged with managing the intersection of these social infrastructures for urban students must do so by fully understanding the dynamics that impact them. As such the study relies upon the Ethics of Care Theory and Multicultural Caring Centered Model as frameworks for examining the perceptions of school leaders.

### **My Story**

The universe has a unique way of aligning individuals with opportunities and experiences that will ultimately shape the course of their lives. As a high school student I was convinced that I wanted to work in the medical field. I participated in HOSA (Health Occupations Students of America) and was driven by the opportunity to care for

others. My mother on the other hand, wanted me to carry the family torch and become a teacher. She always impressed that my desire to care for others would be fulfilled just as it had been for her. As a college intern at a local community organization, I quickly learned that a mirage of economic, social, physical, and educational factors substantiated the sometimes difficult experiences of urban students in schools. It was evident that teachers, stakeholders including families and even community agencies were unequipped with the necessary tools needed to capitalize on the strengths of these students. As such, I became urgently fascinated and inwardly committed to addressing the social causes that often erode urban communities and the experiences of youth living in urban communities.

Instead of heading into the medical field, I pursued a teaching opportunity through an alternative teaching program that would change the course of my life forever. However, the universe has a unique way of aligning individuals with opportunities and experiences that will ultimately shape the course of their lives. Eventually, the educational career ladder landed me in a position as a Pediatric School Teacher at one of the nation's leading Pediatric Cancer Hospitals. How fitting, my childhood dream to work in healthcare would be fulfilled in a manner that I could have never imagined and has been uniquely married with my mom's deepest wishes for me. The universe saw fit to place me at the intersection of health care and education.

Within my new role, my primary responsibility was to operate the secondary education classroom for students' 6<sup>th</sup> -12<sup>th</sup> grade. The students who participated in the hospital education setting comprised of oncology patients who were denied the

ability to attend school in the traditional community school due to their current medical condition. These patients were either immune suppressed, inpatient for an extensive amount of time or simply too medically fragile to navigate the halls of their community school.

The range of educational needs within this setting was extensive and required an extraordinary dedication to implementing unconventional methods. These efforts ensured that students maintained academic involvement despite their diagnosis and treatment plan. Unlike any experience I'd ever encountered in the public sector, my classroom mirrored that of a hospital waiting room. The sight of students constrained to wheel chairs, or connected to IV poles with medication and treatment drips attached were common occurrences. Yet, in this same regards, the image of illness were not always visible, in part due to the exceptional medical practices of our clinical medical team. As discussed quite frequently in the hospital education setting, the students/patients often reflected a tenacity that supersede hardships that would test the strength of even most adults. It became both my natural and moral responsibility to capitalize on the resilience of these students to ensure that their educational needs were meet during all stages of their medical treatment. I was embarking upon a journey known to few!

Yet, despite the commonality they all shared, there existed what seemed to be an innate gap that lingered from my public school experience as an educator. The challenges of being successful within this environment were intensified for students and families of ethnic or low socio economic backgrounds. There seemed to be this

irrevocable burden that manifested in the form of social issues, beyond the consequential impact of their diagnosis--- their needs were substantial.

At the time of my hire, the school program included a program director, 1 school re-entry coordinator and an additional classroom teacher that served elementary school age students. We were housed on the hospital inpatient unit and occupied two classroom spaces and a library designed to service both inpatient and outpatient pediatric patients. We were not identified as a private school at the time and primarily assisted students with their assignments from an online public virtual school, or directly from their community schools. Additionally, the local urban school district in which the hospital was zoned, housed an onsite teacher to meet the needs of their homebound students. The learning environment was designed to sustain a collaborative relationship between the schools, medical institution and families in the important efforts of maintaining academic normalcy.

Over the course of a two year period, our school personnel identified areas of improvement and cultivated avenues to address the emerging needs of our patients both enrolled in our onsite school and those who attended their own community schools. In 2012 the program evolved into a staff of 2 classroom teachers, one of which is dedicated to meeting the needs of our international English as Second Language patients, an Art teacher, and 2 school re-entry coordinators whose function was to serve as a liaison between the patients' multi-disciplinary medical team, community school personnel and the family. In 2009, I transitioned into the role of a school re-entry coordinator and in 2011 the hospital completed a private school accreditation process.

In my current role as Pediatric School Coordinator I am primarily responsible for advocating for the educational needs of our patients and their families I work closely with the medical staff to understand the patients' treatment plan, prognosis and any cognitive, psychosocial or behavioral implications. I am charged with utilizing this information to assist the student/patient, their families and schools in developing a suitable educational plan. My role often resembles a creative mix of educator, social worker, school counselor and health educator.

Much of my time is spent supporting parents in ARD and 504 meetings at the campus level and providing transition support services to ensure that the journey in school is as seamless as possible. I have seen firsthand the implications of significant treatment and the presentation of school avoidance, behavior issues, academic failure and social adjustment among students with chronic conditions. Most difficult has been the seemingly devastating impact that students and their families from marginalized communities experience. As I often reflect, the support provided to families whose English is their second language or those from low socio economic families is often much more aggressive. Limited education often increases the challenges that these families face including managing the school journeys of their student while maintaining care of their sick child. My involvement with these families are not only beneficial but paramount in the transitions of these students during their medical journey.

The journey has been an incredibly rewarding experience but it has also highlighted concern for meeting the educational needs of medically fragile or chronically ill students in general. Limited research has been available in my efforts to

develop effective professional development programs for educators in preparation for establishing quality programs for students in the school setting. This journey has revealed candid policy challenges that impede the progress of medically fragile

students, it has illuminated the struggles for educators, and emphasized communication gaps between medical professionals and educational professionals.

Furthermore, our ability to rely on recent data and published articles to drive the ongoing evaluation of our services were weakened by the lack of reliable sources in the field. For a significant time, virtually no information was available regarding effective hospital/homebound services for students undergoing medical treatment and limited discourse regarding the school re-entry process for these students was occurring.

In capitalizing more intensely on the journey, I am reminded of my patients who have all played a significant role in my reflective experience as a researcher. More specifically, I can reflect upon those students and families whose lives have been shaken to the core as a result of their devastating diagnosis. Patients who were on the brink of academic woes before diagnosis and saw their struggles intensify as a result of treatment. I am reflective of those students whose treatment side effects were minimal but precautions forced their need for homebound services, programming that continues to garner attention. As state policies would have it, students are only allowed 4 hours of direct teacher instruction through most districts homebound programs. The implications of 4 hours of instruction with the expectation that all standards can still be achieved seems unreasonable. The concerns are intensified by the apprehensions of school leaders, teachers and parents who are often forced to play integral roles in the schooling process

of students despite their limited skill set, knowledge and experiences.

I continue to identify areas with the potential to provide significant insight to families, medical professionals and school personnel. My commitment to the research conducted in this research serves as the tip of the avalanche in my journey toward giving voice to the scarce discourse and identifying effective practices for serving students with medical needs. The story would not be pertinent had it not been for the professional opportunity that I began to prepare for many years ago as a college intern.

### **Statement of the Problem**

Improved medical advances have opened an increasingly important discourse regarding school experiences and quality of life for school age students (Georgiadi and Kourkoutas, 2010). In fact, it is reported that 10.3 million children and adolescents are reported to be impacted by a chronic condition that impacts cognitive, physical or psychosocial development (Nabors and Iobst, 2008; Algozzine & Ysseldyke, 2006).

These health conditions are usually unevenly distributed or they disproportionately burden youth and families from low socio-economic status backgrounds (Gold & Wright, 2005). Considering the evolving demands placed on educators and administrators and despite the increasing catalog of research dedicated to addressing the educational and transitional needs of students with chronic health conditions, few pieces of research acknowledges the implications of ineffective policies and school processes that directly or indirectly impact students with chronic illnesses (Irwin and Elam, 2001, pg. 67).

Previous research on the topic of educating chronically ill students asserts that

school personnel have little knowledge about chronic illnesses and feel unprepared to deal with these students in the classroom (Kilebenstein & Broome, 2000). However, limited research is available to support school leaders and their team in developing effective school re-entry or school transition programs for students living with chronic illnesses.

The needs of these students are exacerbated when the intensive realities of poverty, restricted access to quality health care, cultural and linguistic barriers, neighborhood conditions,; as often characteristic of urban communities are added to the equation (Irwin and Elam, 2011, pg. 67). Though significant research, particularly in the area of urban education offers insight into the deterrents of such intrusive realities this research is set to examine the voices of educational leaders and their experiences in this imperative process.

### **Purpose of the Study**

The purpose of this study is to explore the perceptions of educational leaders regarding the educational management of school age students with chronic health conditions. First, the study is being conducted to a.) contribute to a growing but scarce body of research surrounding the management of students with chronic illness, b.) demonstrate a significant need for the ongoing consideration of state, local and national policies surrounding equitable programming for culturally diverse students, specifically those with chronic illnesses c.) establish evidence of best practices for managing the educational experiences of students with chronic illnesses; specifically those within urban communities and d.) establish a suitable communication algorithm for patients,

their families their medical care team, and their school management team.

### **Significance of the Study**

The consequences of this study is paramount and offers opportunities for significant contributions to the educational management of students with chronic illness, particularly in urban areas where a high concentration of health risk exist. The study provides essential insight into the effective implementation of quality programming for chronically ill students within urban schools and communities. Henry-Beauchamp and Sideler (2010), asserts that educators and school leaders in urban areas must “become versed in the identification and treatment of both symptoms and diseases that are endemic to the city environment” (pg. 251). As such, upon evaluating the perceptions of school administrators, the catalyst of the school, results of this study lends itself to providing increased awareness of the implications of health concerns among urban youth, the imperative role of the school administrator in managing students with chronic conditions, improved pre-service programs for school administrators in urban setting, effective school transitions models for students with chronic conditions, and improved communication paradigms between medical, family and school environments. Most importantly, reinforces the need to emphasize the overall academic achievement and social adjustment of ALL students on campus; while cultivating a discourse that will ideally have the strength to impact policy and legislation.

### **Research Questions**

Within this research, I will analyze school leaders’ perceptions of the educational experience of medically fragile students in urban schools by addressing the following

questions:

1.) How do administrators describe **personal characteristics** that lead to managing the school experience of chronically ill students within urban schools or school districts?

2.) How do administrators exercise and interpret their **acts** in the educational management of chronically ill students within urban schools.

3.) How do administrators' describe leadership acts related to the academic achievement of chronically ill students within a recognized urban school district?

4.) How do administrators' describe their leadership acts related to the social adjustment of chronically ill students within a recognized urban school district?

### **Definitions of Terms**

The following terms are defined in the context in which they are used in this dissertation.

**Chronic Illness:** an illness that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaptation in function and is typically referred to as an ongoing health condition.

**Disability:** Any physical or mental impairment that substantially limits one or more major life activities. Per IDEA, it is evident through mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or spec

**Culture:** Often defined by several components including values and behavioral

styles; language and dialects; nonverbal communications and perspectives; world views and frames of references.

**Culture Competence:** A set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross cultural situations.

**Individualized Education Plan (IEP):** The Council for Exceptional Children serves as a written cornerstone for detailing the services as student with disabilities will receive, where these services will take place, and the specific individualized goal of the student.

**504 Plan:** According to Section 504 of the Rehabilitation Act of 1973 (as cited by Irwin and Elam, 2011), any school-age child with a disability, regardless of the nature or severity of the child's disability, is entitled to a free appropriate education (U.S. Department of Education, 2007). The 504 plan is a legal document which includes accommodations needed in order for the chronically ill child student to accept the free appropriate education.

**Other Health Impairment-** Identified as one of the defined disabilities per the Individuals with Disabilities Education Act (IDEA) (P.L.101-476), as having limited strength, vitality, or alertness due to chronic or acute health problems such as heart condition, asthma, and leukemia, all of which adversely impacts a child's educational performance (Knoblauch, 1998).

**School Re-Entry-** The process by which students integrate back onto school campus following a lengthy absence due to a chronic medical diagnosis.

### **The Individuals with Disabilities Education Act (IDEA)- Legislation**

established to ensure that services for students with disabilities are available and governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. ([www.idea.ed.gov](http://www.idea.ed.gov))

**Every Student Succeeds Act-** Education reform bill signed by President Obama in 2015 revising the controversial No Child Left Behind Act. The law includes provisions to advance equity by upholding protection for America's disadvantaged and high need students and promotes high college and career academic standards with great expectation for accountability.

### **Summary**

This paper details my interest in conducting research that offers a concerted effort in addressing the critical care needs of students with chronic conditions. A foundation for the study has been presented which includes: the background of the study, statement of the problem, purpose of the study, significance of the study, definition of terms, theoretical framework, research questions, and the overall organizational structure.

I have also presented a review of literature to include a conceptual framework and critical research analysis including the following topics: the historical evolution of relevant research, a presentation of chronic medical conditions among school age youth, influences on the urban impact, caring centered multicultural leaders, the role of the school leader, school re-entry and homebound instruction, additional related studies and leading collaborative teams.

The research proceeds with identifying and evaluating the methodology of the study in Chapter III. In establishing a solid design by which the study progressed, the research offers a discussion of the participants, research procedures, instrumentation, data collection methods and data analysis procedures. The chapter IV analysis is broken down by the research questions and an analysis of the emerging themes that evolved throughout the scope of the research. In the final chapter, a summary of the findings as it relates to the conceptual framework in chapter 2 is presented, along with any relationship the findings may have with previous studies.

## **CHAPTER II**

### **REVIEW OF LITERATURE**

#### **Introduction**

School leaders serving urban schools have been historically challenged with the draining affliction of ensuring academic productivity within communities that are plagued by substantial inequalities. Spanning the complexities of inadequate resources, disproportionate levels of teacher quality, limited parental support and economic inequities; administrators within urban schools carry a significant burden (Wakeman, Browder, Flowers and Ahlgrim-Delzell, 2006). Despite the uncanny challenges that exude American urbanization, research reveals that successful leaders within community schools must master the implementation of quality programming to support the growth of all students; while simultaneously, sustaining the effective management of school operations (Wakeman, Browder, Flowers and Ahlgrim-Delzell, 2006).

The increasing challenges of social, educational and economic hardship intensifies the scope of school leaderships, as administrators resolve to maintain effective learning climates in a highly scrutinized policy driven era. The Individuals with Disabilities Education Act (IDEA, 1997) requires that all students receive access to general education curriculum and be administered state and district assessments (Wakeman, Browder, Flowers, & Ahlgrim-Delzell, 2006). Compounding the implications of the IDEA mandate is that overall school performance or the annual yearly progress accountability system is highly influenced by the results of these student assessments (Wakeman, Browder, Flowers, and Ahlgrim-Delzell, 2006; Shellard, 2003).

The stakes are astronomical for leaders charged with being instructional leaders in communities where human struggles are magnified by the challenges of educational, social and economic deprivation. Patterson, Marshall and Bowling (2000) inquired “Are Principals Prepared to Manage Special Education Dilemmas?” Special Education in general has long sense been a neglected area of focus for school leaders; however, while interest has certainly peaked in the general special education terms, school leaders have been challenged to account for the instructional success of students with needs that may or may not be managed through special educational policies. Namely, medically fragile students impacted by the diagnosis of a chronic illness or life altering situation. Thus, the integrative challenge of managing educational and health factors within the school environment.

Significant research has been directed toward both urban health and educational disparities; however, it has been done so primarily in isolated focuses. Few researchers, has addressed the intersection of these two societal institutions. This chapter will advance the concepts of “racially, culturally and linguistically responsive research within the context of educational leaders managing the school experience of chronically ill students within urban communities. Subsequent to the ruling of *Brown vs. Board of Education*, the civil rights movement perhaps illuminated not only educational inequities but the increasingly detrimental health inequities that hinder the equitable progression of racially, culturally and linguistically diverse populations (Ford, Moore, Whiting, & Grantham, 2008).

This review of literature provides an overview of research and rationale supporting the study of school administrators’ understanding and perception of instructional leadership practices for urban students with chronic illnesses. The literature review will be

framed through four strands: (1) historical evolution of legislation impacting the educational experiences of students with special needs and chronic conditions (2) chronic conditions and urban issues 3.) school leaders as catalyst of multicultural and cultural competence in serving diverse students with chronic illnesses and 4.) models of school management plans for students with chronic conditions

### **Historical evolution of key legislation**

In 1954 the ground breaking Brown vs. Board of Education ruling given by the Supreme Court substantiated an expansive battle that asserted the imperativeness of desegregating schools, as “in the field of public education the doctrine of ‘separate but equal’ has no place. This landmark case as since served as an inevitable basis for the ongoing insistence that the educational attainment of every child within the United States should include equitable experiences. Reformers, policy makers, advocates and legal experts alike continue to rely on the rulings key terminology to evoke equitable mandates within education and other institutions:

Today, education is perhaps the most important function of state and local governments.

Compulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. It is required in the performance of our most basic public responsibilities, even service in the armed forces. It is the very foundation of good citizenship. Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right which must be available to all on equal terms (Brown v. Board of Education, 1965).

Despite the notable efforts of this ruling and many scholars, American history propels a cyclical continuum of inequities and disparaging disparities that perpetuate the cultures of “racially, culturally and linguistically diverse individuals”. Today, educational leaders are forced to negotiate the implications of these vastly spread inequities and far reaching disparities as their ability to maintain the foundational mandate of *Brown vs. Board of Education* continues to be challenged as a result.

Nevertheless, the groundbreaking ruling inflicted upon school administrators the massive responsibility of providing educational access to ALL students within the public education system (Urban and Wagoner, 2009). The ruling ignited a call to provide equitable opportunities to African Americans and catapulted a Civil Rights Movement that would also substantiate calls to improve educational policies for students with disabilities (Yell, Rogers and Rogers, 1998). It confirmed that the foundation of the Fourteenth Amendment served as the central tenet against segregating blacks and subsequently students with disabilities due to unalterable characteristics (Yell, Rogers and Rogers, 1998).

The 1954 ruling gave rise to the Civil Rights Act of 1964, the Elementary and Secondary Act (ESEA) of 1965 and the Education for All Handicapped Children Act of 1975 which were created to annihilate the inequities faced by individuals of color, low socio-economic status and those with disabilities. Each ruling kindled momentum among advocates, civil rights leaders and policy makers to ascertain that the education of all children were certain.

The Civil Rights Act of 1964 declared for all that discrimination for any reason on the basis of race, color, religion, sex or national origin was illegal in the United States.

Serving as likely the most transformative act in American History it according to Chambers (2008), the courts acceptance of the constitutionality of the Act helped make the act acceptable to a large majority of Americans.

In that same regards, the Elementary and Secondary Act of 1965(ESEA) emphasized equal access to education by establishing high standards and accountability requirements through its funding of primary and secondary education. The ESEA 1965 (reauthorized in 2001 as the No Child Left Behind) was armed to eradicate the extensive achievement gap that has for decades been enhanced by race and poverty. These funding dollars, particularly for schools in impoverished areas was and still today play a crucial role in its operations. This proving extraordinarily important, as it for continues to offer controversial implication for school administrators responsible for the oversight of each campus.

As was evident during 1963-1969, President B. Lyndon Johnson fought aggressively to improve all opportunities for minorities and individuals with disabilities. During this timeframe in American Society Johnson, made not only race and physical abilities a point of concern for policy and programming but poverty by “encouraging the famous ‘maximum feasible participation’ of the less fortunate to empower themselves (Schrave and Jolly, 2010). With federal monies protecting disadvantaged groups, programs supporting not only education but health care, welfare, community development and housing development became an integral focus of Civil Rights legislation.

With the expansion of protection and interest toward students with disabilities, the government implemented the Section 504 Rehabilitation of Act of 1973 a legislation that further tied federal monies to non-discriminatory practices of students with handicaps (U.

deBettencourt, 2002). Further, in 1975 President Gerald Ford signed the Education for All Handicapped Children Act. This comprehensive effort comprised of multiple pieces of many state and federal legislations, finally provided a targeted law protecting the education of students with disabilities (Yell, Rogers, and Rogers, 1998). In 1990, this Act was reauthorized as the Individuals with Disabilities Education ACT (IDEA). Researcher contends, that the IDEA authorization mandates a free, appropriate public education (FAPE) by providing procedural and substantive educational rights to all qualified individuals with disabilities (Yell, Shriner, Katsiyannis, 2006).

Essentially the historical evolution of these Civil Rights Acts and the Civil Rights movement set an immeasurable precedent within schools across the country, especially those in areas saturated with segregation and high poverty. Despite the well intentioned efforts of these Acts, administrators continue to wrestle with the lingering implications of embedded injustices.

It is without struggle that though much headway has occurred schools “often forget that civil rights protections still extend to those students with disabilities who do not qualify for special education under IDEA’s mandates. It is crucial for administrators as catalyst of schools to not only grasp an understanding of the historical significance of legislations that have impacted the equitable education of all students but to also maintain an unbiased clarification of the two most influential laws that most commonly impact medically fragile students within their schools.

#### ***IDEA vs. Section 504***

Beyond understanding the historical context in which students with disabilities have

been served within American public schools, substantial emphasis is rightfully being placed on the contrasting differences between 504 and IDEA. The broadening differences are paramount for students with uncommon or hidden disabilities such as and as a result of chronic illnesses (Shaw& Madaus, 2008; deBettencourt, 2002; Cohen, 1997; Roberts & Mather, 1995; Rosenfeld, 1998). The struggle to recognize the unique needs of children in the school setting is devastating and begins with school leaders' awareness of the most implicating laws.

The Individuals with Disabilities Education Act was officially signed into law by President Bill Clinton in 1997 following several reauthorizations. The law governs all special education services in the United States (DeBettencourt, 2002). The critical emphasis is to maximize the performance and academic achievement of students with disabilities in both the special and general education curriculum (Mitchess, Rogers, & Rogers, 1998). Notably, IDEA is a federally funding program that requires strict management on behalf of school administrators and their staff. In dynamic fashion, IDEA mandates educational agencies to provide a provision of special education and related services to students who meet eligibility via distinct categories of disabilities.

Students with chronic illnesses may qualify for special education services via one of the 13 categories which include: 1.) Autism, 2.) specific learning disability, 3.) speech language impairments, 4.) emotional disturbance, 5.) traumatic brain injury, 6.) visual impairment 7.) deafness, 8.) hearing impairment, 9.) mental retardation 10.) multiple disabilities 11.) orthopedic impairment and 12.) other health impairment. Among these categories, the "other health impaired" category provides individualized educational

programming for children who have long term medical conditions that result in impairments of academic or social functioning (Shaw & McCabe, 2007, IDEIA, 2004). Criteria for “other health impairment” asserts that a student exhibits limited strength, vitality or alertness, including a heightened alertness to environmental stimuli that results in limited alertness with respect to the educational environment that affects his educational performance (DeBettencourt, 2002; Reid & Katsiyannis, 1995). As such, not all students will qualify for special education services under IDEA (Rosenfeld, 1998).

Further, administrators must ascertain that these students receive all services necessary to services through the creation of an individualized education program (IEP) to meet their educational needs. Services such as speech, occupational therapy, physical therapy and nursing care provide a range of options to address the complex educational needs of students with chronic conditions. As a catalyst of the school, administrators should understand fully the requirements of the federal law. The Council on Children with Disabilities contends that the term, “related services” as currently identified in Part A of IDEA includes the following:

...transportation and such developmental, corrective and other supportive services (including speech-language pathology, and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling, orientation, and mobility services, and medical services except that such medical services shall be diagnostic and evaluation purposes) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disability conditions in children

In the cases of not qualifying for these special education and related services through IDEA, justification for servicing the complex needs of students with chronic conditions can

also be identified in Section 504 of the Rehabilitation Act of 1973. Often referred to as a civil rights law, administrators are equally responsible for the navigating the process of improving and implementing services. Under the law, federally funded schools are prohibited from discriminating against individuals with disabilities. Per Section 504, a person with a handicap is:

Any person who has a physical or mental impairment that substantially limits one or more of that person's major life activities, or a person who has a record of such impairment, or a person who is regarded as having such impairment (Section 504, 29 U.S.C. 794)

Essentially, Section 504 mandates that schools are required to make accommodations to ascertain that students are able to access equal educational opportunities (Shaw & McCabe, 2008). These accommodations are purposed with equalizing the educational playing field for students with life altering illnesses and creating a learning environment comparable to all peers. Katsiyannis (2001), emphasizes that accommodations may include structured learning environments, repeating and simplifying instructions, supplementing verbal instructions with visual instructions, using behavioral management techniques, adjusting class schedules, modifying test delivery, using tape recorders, and computer assisted instruction.

While the law is strictly articulated, the continued dilemma of creating equitable and equal learning environments for all students is still a deeply embedded challenge for schools across the country. The growing call to eradicate broken systems, address financial constraints and evaluate policies aimed at monitoring services for students with chronic health conditions is paramount to the role of school leaders. It is imperative that school leadership develops a framework for creating the knowledge and competency to ensure

IDEA and Section 504 compliance (Yell, Shriner, Katsiyannis, 2006). Holler and Zirkel (2008) insists that Principals failure to gain knowledge about the legislation and regulations surrounding these laws could result in costly consequences. More importantly, in urban communities where the issues of personnel training is imperious when dealing with common, economic, educational and social burdens that complicate the experiences of students, specifically those with special needs.

### **Common Chronic Conditions Among School Age Youth**

The work of urban school leaders are greatly impacted by the sociodemographic backgrounds of the student, families and communities they serve. In developing school management plans and procedures for students with chronic illnesses, leaders must fully understand not only the scope of illness within their urban schools, but the systematic issues that come with addressing it. Researchers, in growing fashion contend that school leaders must be reminded of the correlation between children's health and academic performance (Taras & Pottss-Datema, 2005). Further, an increase in the number of chronic conditions among youth within schools posits the need for administrators to place concerted efforts in this area (Perrin, Bloom & Gortmaker, 2011, Proskurowski, Newell, & Vandriel, 2010; Van Cleave, Gortmaker, & Perrin, 2010; Shaw & McCabe, 2007).

According to Lori Anderson (2009), almost 14% of US children less than 18 years of age, or about 10.2 million children, have special health care needs. Of these, 60% have their daily activities affected by their health condition (Anderson, 2009; U.S. Department of Health and Human Services, 2008).

There is great discrepancy among researchers and practitioners alike in regards to

conditions or medical diagnosis' that are considered to be chronic. For many, specifically in the school setting this can greatly impact the practices utilized in serving students with medical needs. Generally speaking however; chronic conditions are recognized as medical conditions lasting more than 3 to 12 months or upon a diagnosis expected to last more than 12 months (Crump, Rivera, Londo, Landau, Erlendson, Rodriguez, 2012; Perrin, Bloom & Gortmaker, 2007). These conditions severely limit ones functions or require medical needs that are not typical among other youth. In regards to school, chronic conditions are also identified by an increased average of days children miss school. Students with chronic conditions or illnesses are absent approximately 16 days a year as opposed to 3 days by healthy students (Shaw & McCabe, 2008; McDougal et al., 2004). More profound illnesses may require students to miss 40 school days a year with some students spending part of the school year in the homebound or hospital school environment. Upon return to the school environment the implications are plentiful.

According to the National Health Interview Survey presented by The U.S. Department of Health and Human Services Centers for Disease Control Prevention (2012), though 83% of most youth under 18 years of age are estimated to have good health, there is a population of youth identified as having a condition that significantly limits daily activities. Kearney (2008), posits that according to the National Center for Education Statistics for 2005 19% of fourth graders missed at least 3 days of school in one month and 7% missed at least 5 days of school within that same time frame.

Utilizing multiple data sources the 2012 report provided estimates for asthma, allergies, attention deficit hyperactivity disorder among a number of other health measures

that substantially impact youth under 18 years of age; thus serving as an infallible resource for school leaders. Of particular importance to urban school environments where air pollution, poor ventilation, chemical irritants, mold and other despicable factors are prevalent; childhood asthma continues to be a relevant point of reference for many researchers (Henry-Beauchamp & Siedler, 2010; Shaw & McCabe, 2008; and Perrin et al., 2007).

Extensive research asserts that school leaders and their staff should have a substantial understanding of students medical needs; as such school leaders should maintain interest in having a full understanding of student needs within the school (Robinson & Summers, 2011; Asprey & Nash, 2006; Gorin & McAuliffe, 2008; Rozsagegyi, 2008; St Leger & Campbell, 2008). School leadership should to take a proactive approach in gaining a formidable understanding of chronic conditions, treatment regimes, side effects and school attendance implications (Shaw & McCabe, 2007). Given the fact that preservice leadership preparation programs do not readily focus on medical conditions or even significant special education conditions, school leaders will benefit having accessing to this information.

In fact, Clay et al. (2004) presented that more than 50 % of a sample of school personnel indicated that their academic training was void of content regarding the management of children with chronic conditions (Nabors, Little & Akin-Little, 2008).

In one literature review, Shaw and McCabe (2008) evaluated the needs of students and determined that the following are key areas of importance: 1.) academic needs, 2.) academic motivation, 3.) social and emotional needs, 4.) adjustment needs and attendance, and 5.) physical needs. Given the scope and varying level of needs that can exist based upon

chronic conditions and other external factors, such processes ensures that leaders are able to overcome any gaps not learned in limited teacher preparation programs.

### *Asthma*

Asthma is one of the most common chronic conditions that affect millions of urban children across the United States. This terrifying condition is the result of inflamed airways of the lungs making it difficult to breathe (acai.org). Symptomatically, asthma generally presents with a nagging cough that worsens at night, wheezing or whistling sounds from constrained lungs, and frequent chest colds (Amr et al., 2002).

Significant to students across urban communities, asthma is most commonly triggered by allergies with studies indicating that 80% of asthmatic children demonstrate a positive test of at least one allergy. These allergens can be induced by both indoor and outdoor triggers consistent to urban environments. Pertinent to urban schools, researchers contend that students spend at least 1100 hours in the school settings where allergen levels within urban schools may exacerbate negative implications on the urban school experience for students with chronic conditions (Amr et al., 2002).

The National Health Interview Survey (2012) estimated that 10 million children have been diagnosed with asthma and a sobering 6.8 children under 18 years of age still suffer from it. Further boys are more likely than girls and 16% of non-Hispanic black children are living with the disease that that makes it harder to move air into and out of your lungs (American Lung Association, 2014). When asthma is exacerbated due to common triggers often found in urban communities and schools children may require intensive management within the school or be required to miss school frequently (Henry-

Beaucham & Siedler, 2010).

In a national study conducted as far back as 1988, a sample of children with asthma grades 1-12 experienced more absenteeism and grade failure than their well counterparts. (Fowler, Davenport, & Garg, 1992). The study also suggested that children with asthma from lower income families posed a double risk of grade failure compared to well children of similar income. Though the results were modest the researchers determined that there is a need for additional research studying the relationship between school functioning and absenteeism among students with asthma (Fowler, Davenport & Garg, 1992). This study certainly confirmed a longstanding notion that students with chronic illnesses

In another cross-sectional analysis of 3812 students, the authors sought to investigate the relationship between absenteeism, presence of asthma and asthma severity level with standardized test level performance in a predominately African American district. Moonie, Sterling, Figgs and Castro (2008) determined that in general absenteeism had a negative impact on standardized test level achievement, as students with asthma performed the same as their non-asthma peers (Moonie et al, 2008). It was revealed that the trend worsened for those with persistent asthma who missed more days of school.

More recently, The Brown University Child and Adolescent Behavior Letter published information on a National Institute of Health funded longitudinal study. From a sample of urban children the study revealed that children with more asthma symptoms experienced poorer academic performance, including grades and quality of school work (Mitchell, 2015). These students also experienced a diminished ability to focus in the classroom. The study also determined that shorter sleep times resulted in poorer asthma and

poorer academic performance. Essentially, the author corroborated previous research acknowledging historic achievement gaps existing among poor and urban students compared to their white counterparts. This issue is heightened as according to Mitchell (2015), urban youth with asthma are at a significant disadvantage for achieving school success. This continues to highlight the longstanding systematic struggles that students of color and those from low socioeconomic backgrounds often face. Their ability to perform is impacted by generational burdens that impede their ability to perform if not appropriately addressed. It is known however; that with the appropriate support system and programming not only can students of color and low socioeconomic achieve but those with conditions such as asthma can learn to effectively manage their home and school experiences (Mitchell, 2015).

### ***Cancer***

Not discussed in the 2012 National Health Interview Survey released by the US Department of Health and Human Services Centers for Disease Control Prevention is information regarding childhood cancer. However; increasing research contributes to a growing body of work for educational leaders and school professionals managing the care of school age students with cancer. McCabe (2010) contends that Cancer is a category of diseases in which body cells mutate and multiply rapidly (pg. 62).

According to Cure Search (2016), childhood cancer is the number one cause of death by disease among children. Additionally, the American Cancer Society (2016) indicates that overall, cancer is the second leading cause of death among youth ages 1-4 years old, second only to accidents. The American Cancer Society approximates that 10,

389 children in the United States under the age of 15 will be diagnosed with Cancer in 2016 (2016). Despite these devastating realities, the advancement of cancer treatment though intensive contributes to a survival rate of five years or more for 80% of children with cancer; increasing 22% since the mid-1970's when the survival rate was only 58% (American Cancer Society, 2016).

More specifically, the annual incidence rate of cancer is 186.6 per 1 million children ages birth to 19 with 1 in every 330 children developing cancer before 19

([www.childcancer.org](http://www.childcancer.org); Ward.E. et al, 2014). Leukemia, is the most prevalent cancer

among pediatric diagnoses. Originating in the bone marrow, this disease disrupts the white blood cells by migrating to the blood, lymph nodes, central nervous system and organs (McCabe, 2010). Approximately, 1 out of 3 leukemia diagnosis are identified as Acute Lymphocytic Leukemia (ALL) and the remaining cases are Acute Myeloid Leukemia (AML). The American Cancer Society contends that chronic Leukemia's are rare in children; with 85% of children diagnosed having a 5 year survival rate. These odds make it extraordinarily relevant to educational leaders in making sure that schools are equipped to effectively the care of these students in the learning environment. Further, ALL is slightly more common in Hispanic children than African American.

Accounting for 26% of childhood cancer diagnoses are brain and central nervous system tumors. With approximately 3 out of 4 youth survive at least five years following a brain tumor or central nervous system tumor diagnosis. Students undergoing treatment will likely encounter late side effects related to chemotherapy, radiation and or surgical interventions (Bruce, Newcombe, & Chapman, 2012, Ullrich, 2009).

Further, research purports that 100% of brain tumor survivors and up to 40% of ALL survivors will experience neuropsychological dysfunction (Nathan, et al, 2007; Moleski, M., 2000; Glauser & Packer, 1991). With attention and concentration impairments being common survivors have also been recorded as experiencing decreased IQ and academic achievement. The varying levels of impact are highly contingent upon the location of the tumor, treatment and age of the student during the time of diagnosis. Other implications of treatment can manifest via slower processing speed, difficulties with visual perceptual skills, executive function and memory (Natan, et al., 2007). Even more so, students who undergo treatment at a young age, will likely experience progressive cognitive deficits that will reduce the likelihood of high school graduation, and offers a high chance of impacting their ability to live independently as an adult (Nathan, et al, 2007). Given this information the educational support services received during the onset of diagnosis and treatment lends itself to influencing the impact of treatment.

### ***Insulin Dependent Diabetes***

Type 1 diabetes Mellitus (T1DM), occurs when the pancreas no longer produces insulin. According to an article published by the American Academy of Pediatrics, this autoimmune disease is a leading chronic disease that impacts approximately 215,000 youth, 20 years of younger. Hoffman and Osipoff (2016), reports that 1 in 400 youth under the age of twenty accounts. Though this chronic diagnosis is well documented, there is limited research fully confirms the prevalence of the disease among youth (American Academy of Pediatrics, 2008).

The shortage of insulin prevents glucose from entering cells and converting to

energy (Taras and Potts-Datema, 2005). Hoffman and Osipoff (2016) asserts that the lack of or reduction in insulin within the body results in glucose increase, and requires the body to seek alternate solutions for energy. In doing so, a buildup of ketones becomes deadly for youth living with chronic conditions. Though Type 1 diabetes is most common in child and adolescents, researchers have reported there is an increase in the number of Type 2 cases among youth. The plight however; especially for researchers and school administrators is that they must be able to help staff leverage knowledge and or resources to manage the disease at school.

Individuals with diabetes must take an ample amount of insulin through subcutaneous injections or a continuous subcutaneous infusion or insulin pump (Hoffman and Osipoff, 2016). This offers a complex concern for medical professionals and parents as dosing accuracy can take time to occur and may result in either too high blood glucose or too low blood glucose. These are factors that can greatly impact the educational experience of school age youth.

In a 2006 study conducted by Wagner, Heapy, James and Abott found that among the 8 to 15 year old students with diabetes assessed in their study, fifty-six percent reported missing class time for routine non-emergent issues. The report also addressed that participants reported frequent diabetes related problems in the school setting which further validates the necessity to analyze the way in which school administrators oversee the management of these students specifically within the school setting.

Hellems and Clarke (2007) asserted that of the 185 parents interviewed in their study, ninety-two percent felt that their child was safely cared for in the school

environment; however, the study revealed that twenty-two percent of the young elementary students were cared for by their parents. With eight-nine percent of the children reporting the need for insulin administration at school, it is always beneficial to every school leader to commit to a systematic process for ensuring proper administration and support. Further, school administration and staff must also be mindful of appropriate meals and snacks for students with diabetes. Getch, Bhukhanwala and Neuharth-Pritchett (2007) suggest that emergency food items should be accessible on campuses to help regulate blood sugar as required. Given the ongoing shortages that often exist in urban schools, specifically this confirms the impact that caring for students with diabetes and other conditions may purport in the overall management of care on campuses.

### **The Urban Influence**

Across these conditions, broad domains beyond medical care have proven to be necessary factors to consider within the school setting. As such, educational leaders have been charged with paying close attention to the details of these conditions and how they can and should be managed in the school environment, specifically urban environments where the pervasiveness of urban factors can exacerbate the implications of chronic medical conditions among school age students. Properly managing these conditions; while simultaneously managing educational programs for school age students can result in supportive learning environments, reduced absences, reduced classroom disruptions, appropriate emergency care responses and full student participation in school programs that maximize academic and social potential (Mitchell, 2015).

Researchers posit that the relationship between health conditions and disparities

begin in the communities and school environments (Carlo, Crockett, Carranza, & Martinez, 2001). In advancing the discussion around health conditions among youth, it is imperative that we understand the factors that lead to the prevalence of various health conditions, the implications of the conditions and or the manner in which professionals are able to manage the conditions in various environments.

Money is among the leading factors influencing health conditions of school age youth as it highlights the socioeconomic disadvantage of students who are often living in poverty. McLoyd (2001) presents an interesting focus on the Family Stress Model that asserts that economic hardship affects the psychological adjustment of school age youth with health problems as an indirect result of the parents' behavior toward the child or their medical situation. It also gives rise to the mental health issues that impacts the social adjustments of students with chronic conditions. In a study conducted by Ceballo & McLoyd (2002), living in high-risk neighborhoods with chronic stressors there appears to be evidence that social support is less effective when attempting to dismantle the economic hardship (2002).

This is important as according to the U.S. Census Bureau (2015), the number of people below the official poverty threshold was 43.1 million with the number continuing to increase through the decades. In 2015, the percentage dropped 1.2 percent from 2014 to a 13.5% rate. As of 2015 two adults with two children below the age of 18 are need only make \$24,339 a year to meet the poverty line.

The implications for poverty not only affect families' economic status but it does contribute to concerns for school administrators who are the primary impactors of

educators. Anon (2005) consequently contends that poverty and other extremes of inequality have enormous implications on urban students and schools. Subsequently low socio-economic neighborhoods also expose students to schools that are insufficiently funded, have fewer qualified teachers, buildings in disrepair and fewer services. Though these factors are more frequent than they should be they are not death sentences and require, school leadership that is equipped to manage students, specifically those with chronic conditions in the school setting.

### **Caring Centered Multicultural Leaders**

Given the increasing intersection between health care professionals and educational leaders, understanding the culture of chronic illness among youth is of growing importance. Despite a colorful landscape of chronic conditions that impact school age children, who, due to medical advances are surviving; researchers assert that professionals do not expect to learn much about chronic conditions in preservice training. As such, Henry Beauchamp and Siedler (2010) contend that professionals in urban areas must become well versed in the identification and treatment of both symptoms and diseases that are endemic to the city environment (pg. 251). School leaders are invaluable in leading these efforts.

This plight is not necessarily an easy one, given the complexity of urban issues that burden the school experiences of these students. Yet, policy and legislation has undoubtedly left little room for administrators to ignore the increasing need of this diverse population (Hoida and McDougal, 1998). In fact, the dramatic change within urban communities over the past four decades has influenced a great deal of research surrounding multicultural education and cultural competency. Yet, scarce attention has been contributed to the

proficiency or practices of administrators and their role in managing the diverse backgrounds of urban students with chronic illnesses. It has become critical for administrators to understand the diversity of their schools and students they serve.

According to Ming and Dukes (2006), multicultural education is means for alleviating achievement gaps; while ensuring the success of all students, including those from diverse backgrounds who also have disabilities or chronic conditions. Given this, Bakken and Smith (2011) emphasizes that school administrators must be competent to work with not only culturally and linguistically diverse students but students apart of other subcultures such as those with chronic illnesses. Understanding culture in regards to students with chronic conditions is important. Though culture is a multidimensional model it focuses on language, symbols and artifacts, as well as customs, practices, and interactional patterns and shared values, norms, beliefs and expectations (Valle 1997; Pang, 2005). School administrators serving students with chronic conditions must not only understand their culture in the traditional sense but also the culture of being medically fragile.

According to Banks (2013), Bullivant refers to culture as a group's program for survival in its environment. It is representative of how the program constructs knowledge and values shared by members in the environment. This too, validates the necessity of a multi-cultural leader who is able to both meet the educational and humanistic needs of students with chronic conditions and develop a school that indoctrinates the perspectives, values and interpretations of their world. A culturally sensitive leader should demonstrate knowledge, awareness, and skills in managing students with chronic conditions (Clay,

2007).

School leaders must model socially competent attitudes, values and dispositions by a.) demonstrating interactions that are shaped by care, understanding and b.) embracing the three principals of culturally relevant and responsive pedagogy (Pang, 2017; Bakken & Smith, 2011). Pang (2017), further asserts that leaders should identify with fostering strong relations with students, specifically those with chronic conditions. At the foundation of these elements, both school leaders must ascertain that their schools are mirrors of empathy, positive school culture and trusting relationships.

This being important there is an obvious gap in the data that communicates how or if school administrators are giving direct attention to the development of these attributes in their practices of managing diverse students with chronic illnesses in the school environment.

### **Role of the School Leader**

It is critical that school leaders understand their role in managing the school environment as it relates to students with special needs such as chronic health conditions. According to Bakken and Smith (2011) proficient school administrators should a.) establish a vision, b.) lead school improvement planning, c.) lead recruitment, hiring, retain and evaluate staff d.) develop curriculum and resources e.) communicate with parents and community members f.) create and support professional development g.) set up systems (manage the school). Understanding the scope of these responsibilities is paramount in building thriving schools that respond to the needs of students with chronic health conditions.

Providing the vision and leadership for instructional programming ascertains that students despite any medical condition are able to reach their maximum potential. It also sets the tone for a school that is inclusive in nature with leadership demonstrating a core norms that are rooted in valuing academic excellence and students' achievement despite any chronic health condition (Diapaola, Tschannen-Moran, & Walther-Thomas, 2004). It directly involves the school leaders setting the tone and values for the climate of the school and communicating that message at every phase turn.

Maintaining instructional balance requires an incredible amount of energy as school administrators are single handily the most important instructional leaders in the school. The discussion of instructional leadership is quite common in general education settings, with more researchers and practitioners giving attention to their role in special education; however the emphasis should also be considered when referencing those with chronic conditions. It is also necessary when students are not able to physically maintain schooling on campus. An excellent leader will continue to facilitate this role through collaborative leadership strategies.

Recognizing that though they are the catalyst of the instructional environment, school leaders are also reliant upon a diverse group of professionals to maintain proper programming for students with chronic conditions. At the pillar of these collaborative professional relationships, all of which should be rooted in the multicultural caring centered framework to support school effectiveness across all professionals. (DiaPaola, Tschannen-Moran, & Walther-Thomas, 2004; Hoy & Sabo, 1998, Hoy, Tarter, & Kottkamp, 1991). It also demonstrates school administrator's abilities and consciousness to ensure that students

with chronic conditions are serviced by qualified personnel. Madaus and Shaw (2008) examined the procedural implementation of 504 plans for students with disabilities or medical needs. Data presented in the study revealed that there is a range of school-based professionals that support the implementation of 504 plans including, general education teachers, school counselors, school psychologists, social workers, and special education teachers (Madaus and Shaw, 2008). . Of the 259 individuals survey 84% served on a Section 504 team. This posits the importance of school leaders establishing a climate of collaborative professional relationships among the team.

Common to urban high poverty environments studies show that students with severe needs such as chronic conditions are more likely to be served by underqualified staff (Voltz & Collins, 2010, Boyer & Mainzer, 2003). A collaborative leader is proactive in their approach in negating this concern while an environment where all professionals are engaged and effective.

### **School Re-Entry and Homebound Instruction**

Significant to managing the school experience of students with chronic conditions is the plight for successful transitions back into the school setting following any extended absences. With the continued importance of addressing both long-term and short-term implications of chronic health conditions understanding the magnitude of this process is significant to curbing issues such as absenteeism, behavioral issues, psychosocial concerns and academic gaps.

Petit and Patterson (2014) took a quantitative approach in what is a rare almost non-existent analysis of homebound programs for students in special education. Utilizing a

survey that allowed researchers examine a national sample of potential homebound service providers and determined that there is a gap in the accuracy of incidences of homebound services. The report also revealed that a majority of the school districts represented in the sample did not have written protocols despite teachers having to document information from their sessions. It was also noted that there is a lack of training designed to prepare service providers. Given the process of school reintegration this is concerning for school leaders who either consciously or unconsciously rely on homebound teachers to maintain an exceptional level of care during homebound services.

Boonen and Petry (2011) also addresses the lack of available empirical data concerning barriers surrounding the educational process for students with medical needs. At the core of this study, is the evaluation of programs that facilitate school re-entry services. These researchers evaluated the perception of parents and students and their homebound instruction and school-re-entry transition. Results revealed that both parents and students perceived their homebound experience to be successful and that it made a positive impact on their school re-entry process. Students and parents in the study confirmed that communication with peers during homebound was maintained and may have played a role in the success of students transitions.

As noted in this study, Bessell (2001) reported a different result indicating that homebound programs were academically inadequate and contributed to social concerns among students with chronic conditions. This is important in the context of how school administrators manage their direct involvement in the care of their students who are both receiving homebound services and those transitioning back onto campus. Likewise, a

preliminary report produced by Searle, Askins and Bleyer (2003) that compared the educational experiences of students undergoing cancer determined that homebound schooling is the least favorable option schooling. Students felt an emotional disconnect during homebound schooling and feared their return to school despite appreciating the academic flexibility of their learning program.

According to Henning and Fritz (1983), a four step framework should lead school re-entry efforts for school age youth upon diagnosis of cancer and other chronic illnesses. These steps include: a.) efforts on behalf of the child must be individualized, b.) availability of experienced professional staff is essential, c.) activities of medical, educational, and social service professionals must be coordinated and d.) each child should be treated as if he will do well in school.

Additionally Henning and Fritz (1983) found that the use of this evidence based model found patients/students showed improvements in attitudes, attendance and achievements. Furthermore, the results also indicated that school re-entry is essential if the child who is able to return to school is developmentally and emotionally intact (Henning and Fritz, 1983).

Leger and Campbell (2007), offers an evaluation of the “Back on Track” program that aims to divert the struggles of maintaining school work and negating school refusal. In a published report Leger and Campbell (2007) aimed to clarify the processes and frameworks of the “Back on Track” program. While the program was implemented in Australia the significance of this research allows for other administrators to utilize the evidence to determine design needs for their service model projects. Similarly, Thies and

McAllister (2001) explained the Health and Education Leadership Project was developed around the principles of family-centered schools which was framed around literature supporting community based programs that fit the family and student's needs. In achieving this, the Back on Track program determined that 1.) developing and maintaining commitment, 2.) utilizing information and communication technologies, 3.) providing teaching support with empowerment focus and 4.) supporting school transition and program withdrawal is critical in creating a school model meet the needs of students experiencing significant absenteeism as result of chronic conditions.

The work of Theis and Leger, have both contributed to the notion that though students with developmental disabilities are often appropriately served in school settings, those students who suffer from the challenge of a life limiting chronic condition are not supported sufficiently (Leger, 2011; Theis, 1999). Theis (1999) offers a significant reminder that these students suffer academically because of a poor fit between their needs and school environments.

During the development of the schools services model, the school leader should evaluate other documented comprehensive school reintegration models to determine which will work in conjunction with the Henning and Fritz's 1983 model (Worchel-Precatt et al., 1998). Further, principles from the ethics of care (Noddings, 2005) and multicultural ethics of care model (O'Pang, 2010 ) can be integrated in the framework established through the mentoring relationship between the expert liaison and school leadership. These models particularly will ascertain that leaders during the management of students with chronic conditions can operate from a critical conscious aiming to ensure that all students are

provided an equitable education; while addressing the achievement gap between mainstream and culturally diverse students (O’Pang, 2010).

Cook-Cottone (2004), offers a school reintegration model that addresses the needs of students with Post Traumatic Stress Disorder. It’s significance provides a formal design for school leaders in meeting the needs of students with chronic conditions This adaptable model identifies a five point plan including: 1.) establishing the relationship with the student, 2.) (PTSD recovery) education topics, 3.) Individualized plan developed, 4.) Facilitated integration with the goal of full day attendance and 5.) Independent integration which signifies independent functioning. This ecological approach offers insight into appropriate systems that school administrators should consider in managing the school experience of students with chronic conditions.

#### **Additional Related Studies**

Bruce, Newcombe and Chapman (2012) evaluated a school liaison program for children with brain tumors that focused primarily on parents and teaching staff. The piloted school liaison program included “assessment of each child and individual family strengths, resources, and educational needs; development of plan to address the instrumental, academic, and emotional support needed; establishment of linkages between health and education systems; and strengthened collaboration between families, school, and staff”. Following the examination of 19 interviews between 9 families, 8 teachers, a school liaison and clinic nurse it was determined that the school liaison should establish realistic expectations and serve as a communication bridge, inform a plan based on realistic expectations, and advocate to meet realistic expectations.

In a single case study, Georagiadi and Kourkoutas (2010) examined the experience of an 11 year old Leukemia patient. Following semi-structured interviews with parents, the student and school staff the study revealed that the intervention utilized focused on increasing knowledge of cancer and treatment side effects and psychosocial implications. The reintegration intervention in the case of this study also included supportive counseling, educational presentations and communication with the medical professionals. Though the study offered a small sample size, the primary participant experienced increased academic achievement.

Dubowy, Kieger, and Songer (2006), took a different approach by utilizing a modular computer based training program that extended professional development training to teachers. After forty-one teacher participants, engaged in the training modules, the researchers determined that there was significant increase in teacher knowledge. Though the intervention did not focus on leadership practices directly, this study offers relevant information to school leaders interested in implementing medical training information to improve the practices of their school staff.

### **Leading Collaborative Teams**

As a school psychologist, Steven R. Shaw has explored the infrastructure of school-based health centers on school campuses particularly in poor urban communities. Though the discussion of school based health services is not the primary focus of my research Shaw in conjunctions with colleagues highlight the convenience of integrating health care with traditional educational functions (Mocow et al, 1997). Further, Shaw offers extensive efforts to communicate the imperative role of school psychologists in the operation of these

school based programs (Moccow et al., 1997; Shaw 2003). His call for increasing the responsibilities and presence of school psychologist in school health care service models is largely rooted in collaborative approaches. Macco, Shaw, Swerdilk, Horton and Foster (1997) contends that school psychologist should be involved with a.) teachers and administrators to monitor the process of instruction; b.) external professionals health, nutritional, or social service matters; c.)parents and caretakers; and d.) individual students in the context of preventive, proactive service delivery. This notion is particularly interesting as there is certainly room to argue that the implementation of a school based health center in urban schools would greatly influence the schools capacity to better serve students with chronic conditions.

With the core charge of utilizing school psychologist to encourage instructional and developmental outcomes for children; especially those with chronic conditions it is necessary to include school psychologist in efforts to reduce barriers toward achieving positive development and instructional outcomes (Shaw, 2003). As such, Shaw evaluates training models for school psychologist interested in working in school based models of care. His call for a structured training model is coherently necessary as it validates significant research suggesting school staff feels unprepared to handle chronically ill students in school settings. Further, this contribution to the growing body of research supporting the integration of health care models in the school environment highlights the ongoing call to diversify a multi-disciplinary team of professionals to meet the growing needs of students.

Shaw, Clayton, Dodd and Rigby (2004) provide critical insight into improving the

collaborative relationships between physicians and educators. Recognizing that the meaning of disability or chronic health conditions differ by definition between the hospital and school setting their research underscores the necessity to develop models of effective collaboration between the two entities. With 10 million school children having some form of a chronic condition, the collaboration between the medical professionals and school psychologist requires targeted response to student needs via various services including, homebound instruction, section 504 programming, and Other Health Impaired Services (OHI) (Shaw & woo, 2007). The implications are significant and as my work attempts to expand upon evaluating the roles and consciousness of school leaders in the process of managing students with chronic conditions; I will rely on Shaw's contributions to best practices, trends in health care delivery and collaborative models between schools and health professionals (Glaser, Ouimet & Shaw, 2010; McCabe & Shaw, 2010; Shaw & McCabe, 2007; Shaw & Woo, 2007).

### **Summary**

In closing, the literature presented represents a small but growing foundation of evaluating the management of students with chronic conditions. It leverages scarce pockets of research and evaluates the role of school administrators in the process.

Research with this direct focus is essentially non-existent but information regarding leadership characteristics of school administrators is applicable in the directly managing programs that address the needs of students with chronic conditions. This review sets the historical precedence of caring for students with needs beyond what has been deemed as normal and lends itself to necessity of evaluating policies that address the growing diversity

of students in schools.

## **CHAPTER III**

### **METHODOLOGY**

#### **Introduction**

Urban leaders are faced with the ongoing challenges of educating an ever increasing lineage of diverse learners with incredible needs. With increasing accountability, the advent of sensationalized media reporting, a multitude of funding limitations and challenging testing constraints, leaders are required to forge through and ascertain that exceptional educational programming is an achievable reality for all students (Kincheloe, 2010). Given these demands, pundits across various academic disciplines have identified and analyzed the implications for urban principals whose abilities to ensure such excellence is challenged by longtime systematic inequities and social injustices---thus intensifying this process for school leaders and learners.

Kincheloe (2010), identified a list of twelve unique characteristics that increases the complexity of leading urban schools. Significant to this research are the following assertions: a.) urban schools function in areas marked by profound economic disparity, b.) poverty- stricken youth are likely to experience health problems c.) have higher rate of ethnic, racial, and religious diversity, d.) serve higher populations of immigrant populations, and e.) characterized by linguistic diversity. Despite these revelations the challenge for urban administrators is to succeed in spite of. There is an increasing call to address these existential needs among urban youth by addressing these complex intersections and assuring that all students are successful (Kincheloe, 2010).

Of particular interest to this study, is evaluating the approach that leaders take (or

not) in capitalizing on the schools' capacity to provide educational services for students impacted by chronic health conditions; specifically ethnic minority students living in poverty (Kumagai, Lypson, 2009; Capella, Frazier, Atkins, Schoenwald and Gilsson, 2008). The importance of such inquiry is driven by cyclical indications that health care disparities continue to ignite repetitive inequalities in education, housing and employment (Kumagai and Lypson, 2009). Knowing this, urban leaders are charged with analyzing programming efforts that directly impact culturally and ethnically diverse student populations with chronic conditions.

This study offers a reflective evaluation of two intersecting institutions that greatly impact the overall functioning of students in urban communities—health care and education. In an appropriately parallel opportunity, Kumagai and Lypson (2009), asserts that in addressing the health care needs of patients, providers much like school leaders must develop a critical consciousness that recognizes problems within urban communities and societies in general and develop solutions accordingly. In doing so, these paralleled practitioners (should) pursue outcomes of multicultural social justice and is characterized by...

the open acknowledgement of the dignity and autonomy of, and delivery of high quality medical care to all members of society, regardless of gender, race, ethnicity, religion sexual orientation language, geographic origin or socioeconomic background.

Essentially, given the increasing nature of school accountability and performance, administrators within urban schools are forced to maintain a pulse of the present and developing struggles of their students both within the school and outside

environment. As such, evaluating the most pressing health conditions among students within urban communities and developing solutions to ascertain that quality school services are maintained is imperative.

### **The District**

The voices of school administrators within an urban district located in the southeastern region of Texas. The urban district spans 57 miles north of the fourth largest urban city in the United States of America and boast an extraordinarily diverse population of students. Quickly increasing in size, the district serves approximately 36, 484 students with 74.0% of students being economically disadvantaged and 19.48% of the students are limited in English proficiency.

Demographically, the student population is comprised of 42.63% Hispanic, 39.87% African American, 11.25% white, 3.67% Asian, 1.20 percent American Indian/Alaskan and .13% Hawaiian/Pacific Island. According to PEIMS data, the district also reports 1.2% as two or more. With corporate growth evolving with the community, it the diversity of is expected to expand in the near future.

At the high school level, the district consists of 3 large 6A schools, an early college academy, a career academy and an online virtual school. There are 7 middle schools serving 6-8<sup>th</sup> grade students and 26 elementary school providing educational services to Pre-K- 5<sup>th</sup> grade students. Over 4,727 professionals assist in the operation of this urban school district and of specific importance 151 administrators and Principals lead 2796 teachers and other professionals and 470 aides.

There is currently no immediate breakdown of the number of students being served with chronic conditions. The district does employ 1 full-time LVN nurse at the elementary level at each campus, 1 RN at the middle school and 2 full-time RN's at the high school level.

## **School Communities**

### ***House of Healing 1***

Located on the West side of the district, this community serves 775 students serving grades Early childhood through 5<sup>th</sup> grade. The House of Healing earned a Met Standard rating in 2016 and a Distinction Designation for academic achievement in English Language Learner and Reading. The school community currently projects a 96.4% attendance rate, with 83.6% of the students being economically disadvantaged, 44.3 % being English Language Learners and 6.3% are special education identified. The demographics are as follows: 28.4% African American, 55.4% Hispanic, 8.3% White and 5.4% Asian American. The last accountability report card confirms that the school is recognized in the top 25% for student progress and closing performance gaps.

### ***House of Healing 2***

Serving 720 students in grades early childhood through 5<sup>th</sup> grade. With 29.4% African Americans, 54.9% Hispanic, 3.2% White, 1.3% American Indian and 9.9% Asian American the school community has a 97.1% attendance rate. The school sits in the West area of the district and is 77% economically disadvantaged, 43.8% of students are English Language Learners and 6.3% of the students are enrolled in special

education services. In 2016, the school Met Standards per the state accountability report card.

### ***House of Healing 3***

Per the 2016 state accountability report card this 710 student school community Met Standards. The school has a 95.9% attendance rate. Serving grades PK-5<sup>th</sup> the school community has a 27.8% African American student population, 44.7% Hispanic population, 19.4% White student population, 1.6 % American Indian population and 1% Asian. The school is 32.4% economically disadvantaged, 16.2 % ELL and 6.7 % special education.

### ***House Healing 4***

Earning a distinction designation in Science, this community is made up of 502 PK-5<sup>th</sup> grade student population. Demographically the school is 21.7% African American, 32.7% Hispanic, 37.5% White, and 1% American Indian. Meeting Standards per the 2016 Accountability Report Card, 52.8% of the students are economically disadvantaged, 9.2% are English Language Learners and 6.0% are identified as special education. The community received a distinction designation in science. The campus is boast a 100% highly qualified staff.

The table below offers a comparative graphic of each house of healing:

**Figure 1. Demographics of Each House of Healing**

<b>House of Healing</b>	<b>Students Served</b>	<b>Attendance Rate</b>	<b>Economically Disadvantage</b>	<b>EEL Learners</b>	<b>Special Education</b>
1 (EE-5 <sup>th</sup> )	775	96.4%	83.6%	44.3%	6.3%
2 (EE-5 <sup>th</sup> )	720	97.1%	77.0%	43.8%	6.3%
3 (PK-5 <sup>th</sup> )	710	95.9%	32.4%	16.2%	6.7%
4 (PK-5 <sup>th</sup> )	502		52.8%	9.2%	6.0%

<b>House of Healing</b>	<b>African American</b>	<b>Hispanic</b>	<b>White</b>	<b>Asian</b>	<b>Indian America</b>
1 (EE-5 <sup>th</sup> )	28.4%	55.4%	8.3%	5.4%	
2 (EE-5 <sup>th</sup> )	29.4%	54.9%	1.3%	9.9%	1.3%
3 (PK-5 <sup>th</sup> )	27.8%	44.7%	19.4%	1.0%	1.4%
4 (PK-5 <sup>th</sup> )	21.7%	32.7%	37.5%		1.0%

### Sample

A **purposeful** sample was utilized for this study, allowing the researcher to generalize data from a population of school administrators (Gall, Gall and Borg, 2007). Further, purposeful sampling seeks to include cases that are “information-rich” with participants who have the experience to provide a deep insight and understanding of the phenomena (Patton, 1990; Bogdan & Biklen, 1998; Merriam 1998; Gall, Gall and Borg, 2007). More specifically, Patton (1990) contends that:

the logic and power of purposeful sampling lies in selecting *information-rich* cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling.” (p.169)

Furthermore, without interaction, purposeful sampling and emergent design are impossible to achieve (Lincoln & Guba, 1985).

In addition to generalizing the data to a specific population, the researcher

provided descriptive characteristics of the sample and provide justification for why the sample was appropriate for the study (Gall, Gall and Borg, 2007). Merriam, confirms that the researcher must indicate selection criteria when choosing the people or sites to be studied (Merriam, 1998). As such, this study relied on elementary school administrators for the following reasons: a.) foundational learning experiences are paramount to the long term success of students b) students undergoing significant medical treatment at a young age are likely to experience cognitive side-effects

Moreover, the criteria for the selection of participants will be as follows:

- 1.) School leaders with a minimum of 3 years of experience in serving in the Principalship capacity.
- 2.) Is currently serving in the capacity of Principalship or assistant principal within the selected school district
- 3.) Currently serving in an elementary school within the selected school district
- 4.) Have at least 1 student on campus with an identified chronic medical illness or a student currently out on homebound due to a chronic medical illness and is expected to return to campus during the current school year

### **Procedures**

The initial phase of the research consisted of receiving approval from the Texas A&M Institutional Review Board to conduct the this study. Permission from district leadership and school administrators proceeded the Institutional Review Board approval. I developed standard interview guides designed with questions that drove the flow of the interviews. Prior to formally utilizing the interview guide, the instrument was viewed by

several administrators and experienced professionals to ascertain the reliability of the instrument and that it was designed to collect the most appropriate information possible. Suggestions for revisions and corrections was reviewed and the instrument was finalized.

Upon receiving approval of the interview instrument, researcher conducted interviews. During all interview sessions, researcher utilized a tape recorder app to record conversations to allow for transcription of interviews. Four participants responded, were eligible and interviewed.

### **Positionality**

Relying on a qualitative methodological approach to this study, I serve as the human instrument to communicate the perceptions of administrators on the educational management of chronically ill students in schools. With data being filtered through the interviewer during the interviews and the data analysis, “qualitative research is inexorably linked to the human being as the researcher” (Meloy, 2002, p.108). Given the primary focus of understanding within qualitative studies, the human instrument offers an infallible opportunity to ascertain responsiveness and adaptability while collecting and analyzing data (Merriam, 2009). Lincoln and Guba (1985) in early research explicated:

Naturalistic inquiry is always carried out-logically enough in a natural setting. Such a contextual inquiry demands a human instrument, one fully adaptive to the indeterminate situation that will be encountered. The human instrument builds upon his or her tacit knowledge as much as, if not more than, upon propositional knowledge and uses methods that are appropriate to humanly implemented inquiry: interviews, observations, document analysis, unobtrusive clues and the live (p. 187).

Interviews and open-ended questions served as the primary source of information received from the participant's interpretation of their perceptions' on the educational management and best practices for serving chronically students within urban schools. Gall, Gall and Borg( 2009), the common use of interviews permits "open-ended exploration of topics and elicits responses that are couched in the unique words of the respondents" (p. 229). In the case of this research, I utilized a naturalistic interview guide approach to report the participants' own words to explore each participant's interpretations relating to factors and their processes for managing the learning experience of students with chronic illnesses. The interview guide was constructed based upon critical issues leveraged from the review of literature, as well as questions formulated by my own experience and inquisitiveness with the intentions of gathering information relating to managing students with chronic conditions.

The interview guide approach to naturalistic interviews aided in developing first by generating a list of concerns to be presented to each participant, with the intent of permitting other topics to evolve throughout the interview sessions. The interview guide in this study will consisted of: a.) background and career information b.) qualities and effectiveness c.) impact of effective leadership, d.) training and development of administrators serving medically fragile students and e.) managing in urban environments.. Though questions will be predetermined, a vital role of the researcher will be to ensure flexibility in generating new questions as the interview is carried out (Merriam, 2009). Follow-up interviews will occur to allow researcher to gain clarity as

necessary or verify information presented during initial sessions.

### **Data Collection**

Following approval to conduct research from Texas A&M University's Institutional Review Board, I will use a general interview guide to allow me to provide a common set of topics from which data will be retrieved. I will also seek approval from district leadership. Once approval from the district is received, participants who meet the studies criteria will be contacted. Selected and willing participants will be interviewed individually in a comfortable environment conducive to the participant's schedule. Interviews are expected to last approximately 60 minutes.

According to DeMarris(2004), Merriam states that an interview is defined as “a process in which a researcher and participant engage in a conversation focused on questions related to research study (2007, p. 55). Merriam (2009) also

asserts that interviews are the best way to gather information needed. More importantly:

A structured interview seeks to determine the frequency of pre-conceived kinds of things, while the unstructured interview seeks to find out what kinds of things exist in the first place. It forms a close link with participant observation, in which much data is gathered by informal interviewing; observation is part of the method of in-depth interviewing (Lofland & Lofland, 1984, p. 157)

As the researcher, I relied on audio-taped interviews, recorded field notes, non-verbal cues and observations will be used to analyze non-verbal cues. According to Wolcott's (1992), collecting data is “about asking, watching and reviewing” (Merriam, 2009 p. 85). In doing so, varied forms of data collection will lend itself to the process of triangulation, allowing myself as the researcher to develop a comprehensive

understanding of the phenomena of administrators managing the educational experience urban students with chronic illnesses (Carter, Bryant-Lukosius, DiCenso, Blythe and Neville, 2014).

Prior to the interview human subjects form will be submitted and participants will be granted assistance of personal confidentiality.

### **Research Design**

This research study followed a qualitative phenomenological examination of the shared experiences of elementary school principals and their management of students with chronic health conditions. Creswell (2007), asserts that phenomenology helps to “reduce individual experiences with a phenomenon to a description of the universal essence” (pg. 58). Further this inquiry yields insight into what people experience in regards to some phenomenon and how individuals interpret the phenomenon. It is centered on the descriptive premise of a “lived experience”. This framework is being considered to gain an understanding of how these school leaders exercised and (reinterpreted) their leadership regarding the management of students with chronic illnesses. The intent of the study is to broaden the very limited research base relating to the experiences of school leaders, whose voices can inform others about the pertinent issues of serving students with chronic conditions. In order to develop a clearer understanding of the administrators’ perceptions on their role in the educational management of students with chronic illnesses, this study will investigate constructed meaning of the relationship between their perceptions, knowledge and the way they lead.

For this study, I utilized a qualitative research method to gain an in-depth

understanding of the personal and professional characteristics, perceptions on the ways of leading and approaches to the academic achievement and social adjustment of students with chronic conditions. Research states that the best qualitative methods come easier to the human instrument, as qualitative methods are stressed within the human naturalistic paradigm (Lincoln & Guba, 1985). Under this notion, the human instrument favors methods that are extensions of normal human behaviors, such as observing, listening, speaking and reading.

Qualitative research is based on an interpretivist epistemology, where the social reality is seen as a set of meanings that are constructed by the individuals who participate in that reality. The purpose of this study is to discover those meanings. According to Merriam (1998), qualitative research offers an overarching interest in understanding the meaning people have constructed, and an inductive approach to knowledge generation. I served as the primary instrument for data collection and analysis, with the goal of producing a product that is both narrative and descriptive in nature.

In my efforts to develop an understanding of how administrators contribute to the management of chronic ill students, I determined that interviewing will provide an opportunity for interviewees to tell their stories. Miles and Huberman (1994) contends: Qualitative data with its emphasis on people's "lived experience", are fundamentally well suited for locating the meanings people place on the events, processes, and structures of their lives and for connecting these meanings to the social world around them (p.10).

## **Complementary Data Gathering Techniques**

In order to gather additional data, several other strategies and techniques were utilized. In an effort to enhance the collection and interpretation of the data these strategies were used. The use of tape recording, field notes, and non-verbal cues are discussed in this section.

### ***Tape Recordings***

Participants were interviewed using an iPad recording program. The transcriptions were completed, reviewed and corrected by the researcher.

### ***Field Note***

In an attempt to compare a written document of the observations, dialogue, experiences, and perceptions of the participants and the events that influenced them both directly and indirectly, I collected notes during the course of my visit and interview.

Field notes served the purpose of recording my feelings, thoughts about the investigations, and maintained a way of retaining records. Notes were transcribed quickly after the interviews and interactions took place.

### ***Non-Verbal Techniques***

Applying techniques suggested by Lincoln & Guba, body movements, use of time as in pacing, pausing, probing, voice quality, volume, voice inflections and touching were utilized to record non-verbal cues. As a result of non-verbal cues, I asked follow-up questions during interviews to ascertain I was recording the full meaning of participant's response.

## **Trustworthiness and Credibility**

The process of building trustworthiness in naturalistic inquiry is critical (Lincoln & Guba, 1985). The criteria for building trustworthiness are credibility, transferability, dependability, and confirmability. In order to enhance trustworthiness and credibility in this study, I will use an audit trail reflecting triangulation of the data through the use of interviews, observations, recorded field notes, and individual interviews. Understanding that access to multiple sources leads to increased understanding of the phenomena being studied (Bogdan and Biklen, 2003, p. 107). Comparing the transcribed notes, I was able to validate emerging themes, make corrections as necessary and identify areas for further analysis when necessary.

### **Member Checking**

Member checking, according to Lincoln and Guba (1985), is the most crucial technique for establishing credibility. It is a process which involves participants verifying data and interpretations collected through the interviews. In the case of this study, as themes and categories emerged, and any clarification proved necessary, the analyzed data was shared with the participants for reaction, response, clarification and verification.

### **Transferability**

Transferability has been recommended as the qualitative counterpart for external validity (Lincoln & Guba, 1985). They also stated that “if there is to be transferability, the burden of proof lies less with the original investigator rather than with the person seeking to make the application elsewhere” (p. 298). Essentially, though the researcher

seeks only to describe one specific situation and the meaning of that particular situation for the participants of the study, the reader of the research report can apply the findings of the research to similar situations in which he or she is involved.

Lincoln and Guba (1985) stated, the transferability will depend upon the situation to which the reader applies the findings of my study. Lastly, Lincoln & Guba (1985) stated that “the naturalistic cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility” (p.316). Given this, my intent with this study is to give readers an opportunity to apply this aspects of this work to situations that they are involved with.

### **Dependability and Confirmability**

Dependability, which is the naturalist’s substitute for reliability, can be demonstrated by “taking into account both factors of instability and factors of phenomenal or design induced change” (Lincoln and Guba, 1985, p. 299). To establish dependability, I examined all records for accuracy and substantiated documents.

Confirmability, was utilized during the data collection and analysis phases to verify and construct findings that may be important to increase what is already known about administrators managing students with chronic conditions. To demonstrate confirmability, I maintained a record of the inquiry process, copies of each taped interviews and discussions, notes from interviews and discussions, and hard copies of all transcriptions. In addition, records are available upon request.

## **Plan of Analysis**

The data analysis is a vital component of the research process and occurs simultaneously with the data collection (Merriam, 2009). It is the process by which the researcher relies on a framework to understand the human behavior within which participants interpret their thoughts, emotions and behavior (Marshall and Rossman, 1989). In my attempt to make sense of the data collected, which is in essence the primary purpose of the analysis process; I utilized a procedure known as an inductive analysis (Lincoln and Guba, 1985; Merriam, 2007; Bogdan and Biklen, 2007).

Given the exploratory and descriptive nature of qualitative research an inductive analysis offered an opportunity to “derive a process, identify factors that shape the process and how the process influences the way administrators see themselves (Huberman and Miles, 1994; Merriam, 2007). To accomplish this, my research was grounded in the assumption that features of the social environment are constructed as interpretations by individuals and that these interpretations tend to be temporary and situational.

I used a recording app and transcribed data sets, and engaged in the process of unitization. Lincoln and Guba asserts:

Units are single pieces of information that stand by themselves; that is, they are interpretable in the absence of any additional information. A unit may be a simple sentence or an extended paragraph, but in either case, the test of its unitary character is that if any portion of the unit were to be removed, the remainder would be seriously compromised or rendered uninterpretable. (p. 203).

In general terms, it is the process of coding then identifying units in the collected data set that answers the presented research question (Merriam, 2009; Gall, Gall and

Borg, 2007).

As the researcher I identified the categories as the next step in the research process. This being a critical process to ensure that the important constructs, themes and patterns emerged.

## **CHAPTER IV**

### **FINDINGS**

#### **Introduction**

This analysis depicts the voices of four school administrators and their role in the management of students with chronic conditions within their urban schools. The first section offers a descriptive illustration of each participant, as I utilized their words to convey a rich representation of the phenomenon through their stories. Each of the study participants were assigned a pseudonym to mask their identities for the purpose of protection and confidentiality. As the researcher, I relied on gathering data through observations, interviews, and audio recordings and was therefore able to assign pseudonyms representative of the participants' personality traits, voices, and backgrounds through this data collection process. In an estimated 38 question interview, the following five categories were targeted based on Chapter II Literature Review: a.) background and career information b.) qualities and effectiveness c.) impact of effective leadership, d.) training and development of administrators serving medically fragile students and e.) managing in urban environments.

The presentation findings are organized in the following manner: a.) an introduction and description of each participant b.) an individual review of interview responses by each school administrator, and c.) the presentation of themes and subthemes arranged among three research questions that guide and serve as the foundation of this study:

1.) How do administrators describe personal characteristics that lead to managing the school experiences of chronically ill students within urban schools or school districts?

2.) How do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities?

3.) How do administrators' describe their leadership acts related to the academic achievement of chronically ill students within a recognized urban school district?

4.) How do administrators describe their leadership acts related to the social adjustments of chronically ill students within a recognized urban school district?

The semi-structured interview questions were open-ended in nature and provided a foundation for participants to articulate their stories (Appendix C). In an effort to elicit non-biased responses, as the researcher I remained cognizant that their stories could only be told through my documentation of their body language, their tone, and their facial expressions both during and after the interview. After reviewing in detail a combination of non-verbal observations in conjunction with their stories told during the course of the interviews, during the re-listening of the recordings, and the numerous rereading of the transcribed manuscripts, the following major sub themes evolved: hiring the right staff, training and development, admin support or lack thereof from central office, instructional leadership, effective communication, knowledge of laws, caring and understanding, and personal experiences with chronic conditions.

The emergence of subthemes allowed for the evolution of 3 major categories

during the evaluation of the data. The categories included: 1.) lead with a moral compass, 2.) create an inclusive culture and 3.) transformational leadership. As the findings are presented these themes were identified as data for each research question being addressed in this study.

### **Welcome to the House of Healing**

There is certainly an ongoing effort to remedy the struggles of education and the effective operation of schools across this country as evidenced by years and years of proposed reform efforts. At the forefront of these energies, significant attention continues to highlight the role of school leaders in the endless journey of educating all students regardless of their uniqueness. As educational leaders within a system that has yet to fully realize equitable outcomes for every single student across the country, their role is monumental in prescribing just the right dose of attributes within our schools or houses of healing if all students are to achieve academic and social success. As such, the presentation of data is metaphorically embedded within an illustration that strategically marries the characteristics of health care and educational institutions. The goal at the end of this chapter is to present voices of remedies that are all currently contributing to 4 houses of healing (schools) and their role in the care of students with chronic health conditions within schools across urban communities and beyond. We will navigate perceptions, acts, interpretations and practices, that these voices of remedies contribute to their house of healing and glean what is valuable in addressing any gaps that are significant in properly and effectively ensuring that students with chronic conditions are well managed in these environments. In the table below, you will first meet the

overseers of the four houses of healing whose voices and experiences are represented in this study.

**Figure 2. Meet the Participants**

<p style="text-align: center;"><b><u>Chris the Compassionate</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 25<sup>th</sup> Year in Education</li> <li><input type="checkbox"/> 4<sup>th</sup> year at current campus</li> <li><input type="checkbox"/> Texas Southern Graduate</li> <li><input type="checkbox"/> B.S. in Elementary Education with concentration in Math</li> <li><input type="checkbox"/> Master's Administrative Leadership- Prairie View A&amp; M University</li> <li><input type="checkbox"/> 1<sup>st</sup> African American Principal at his school</li> <li><input type="checkbox"/> Son of a 35 year retired educator</li>   <li><input type="checkbox"/> <b>Chris the Compassionate thrives on giving his camps a dose of compassion and understanding as a leader.</b></li> </ul>	<p style="text-align: center;"><b><u>Eve the Exuberant</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 17<sup>th</sup> Year in Education</li> <li><input type="checkbox"/> 3<sup>rd</sup> year at current campus</li> <li><input type="checkbox"/> Graduate of University of Houston- Downtown</li> <li><input type="checkbox"/> B.A. in Business</li> <li><input type="checkbox"/> Alternative Certification Program</li> <li><input type="checkbox"/> Master's Administrative Leadership- Prairie View A&amp; M University</li> <li><input type="checkbox"/> Enrolled in doctoral program at Sam Houston State in Education Leadership</li> <li><input type="checkbox"/> 12 years in current district</li>   <li><input type="checkbox"/> <b>Named because her energy and excitement for community and collaboration is contagious. She offers just the right dose of</b></li> </ul>
<p style="text-align: center;"><b><u>Daniel the Disciplined</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 16<sup>th</sup> Year in Education</li> <li><input type="checkbox"/> Retired after 22 years in Marine Corps</li> <li><input type="checkbox"/> 5<sup>th</sup> year at current campus</li> <li><input type="checkbox"/> 9<sup>th</sup> year as administrator</li> <li><input type="checkbox"/> B.A. in Psychology from University of Maryland</li> <li><input type="checkbox"/> Master's in Elementary Education Wheelock College</li> <li><input type="checkbox"/> Ed.D Education Leaderships from Sam Houston State University</li> <li><input type="checkbox"/> Education is a 2<sup>nd</sup> Career</li>   <li><input type="checkbox"/> <b>His name was influenced by the structured mandates of his father and his 20 plus years of experience in the service. He provides a dose of discipline and order to his campus.</b></li> </ul>	<p style="text-align: center;"><b><u>Shane the Servant</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> 25<sup>th</sup> Year in Education</li> <li><input type="checkbox"/> 1<sup>st</sup> year at current campus</li> <li><input type="checkbox"/> 16 years of school leadership experience</li> <li><input type="checkbox"/> Graduate of Southern University</li> <li><input type="checkbox"/> B.S. in Elementary and Middle School Math and Science</li> <li><input type="checkbox"/> Master's in Administrative Leadership- Southern University</li> <li><input type="checkbox"/> Father is a retired Principal in a small Louisiana Parish</li>   <li><input type="checkbox"/> <b>Shane the servant encourages his staff to lead with a heart of service and therefore, administers his own dose of servitude to his campus daily.</b></li> </ul>

**Interview 1**

**Meet Chris the Compassionate** who operates by thriving on giving his campus a dose of compassion and understanding. Journey with me as I visit his house of healing.

Eagerly anticipating the start of the interview, I was a bit anxious and arrived at the first destination approximately 35 minutes early. The weather was muggy during my 55 minute commute and set the stage for my arrival to this quaint little school nestled in the wooded area of an older neighborhood. Landscape was simple and like older schools I immediately become reminiscent of my elementary days both as a student and young teacher. My attire seemed perfect for the occasion as my black and white small checkered slacks, white blouse and long sweater cardigan adorned with a red neckless gave off the ultimate teacher vibe. As I waited in the car, I tripled checked my folder with my interview guide, consent and district approval form...however, most pressing was confirming that the recording devices were prepared and ready to go.

Upon entering the school, I immediately noticed a poster on the wall that read, "Are you or your family Migrant Workers?". I hadn't engaged in a thorough demographic search of the school, so as to not embed any perceptions or prejudgments but I recognized that the school likely served a diverse group of students. To my right was a large glass window that protected the office staff with one open window allowing for communication. I introduced myself and acknowledged that I had an appointment with the school administrator for an interview. As in most schools, she swiped my driver's license, provided me with a guest sticker and directed me to have a seat.

As I sat in the lobby, I was able to take in the distant sounds of teachers and students as they travelled the hallways and participated in what seemed to be an axillary class of some kind. The overall tone of the school was quiet, and the festive holiday spirit, as evidence by a large decorated Christmas tree provided a very comfortable feel

in the lobby. During my wait, I witnessed a parent who arrived to make arrangements for an extended international trip for her two sons attending the school. She wanted to notify the school of their upcoming absences prior to leaving as they would be rushing to catch a flight to Egypt. The staff member was excited to hear of the family plans and expressed how excited the boys must be. They were heading to visit their grandmother and was in for a very long flight. I couldn't help but envy this amazing opportunity to travel to such a place and was also reminded of the *migrant poster* that caught my attention. Knowing your school population is essential and this connection contributed to culture of this school.

As I sat in a very comfortable chair that certainly added to the feeling of home in the lobby, I was drawn to the television that rotated updates and pictures of events around the school. Several of the messages were in Spanish so I was unable to comprehend, but the pictures of school programs and parent meetings resonated. Before long a class of predominately Hispanic students began to transition from a room behind me. They walked in line, and were excited to see their teacher.

Shortly thereafter, I was greeted by a slender man wearing a blue suit and glasses. "Mrs. Hayes, you can follow me". I grabbed my belongings and trailed him through the glass doors and down a hallway that housed several lines of students who seemed to be transitioning to other classes. Friendly greetings were exchanged as both teachers and students passed the administrator. He responded but carried a sense of purpose...he seemed to be focused. One young man stopped and very politely said, "you can pass" giving Chris the Compassionate and myself the right-a-way to cross into a

large room.

I was signaled to have a seat on the left side of a group of desk or small tables that had been pushed together to resemble that of a large conference room. Seated at the end of the tables was another young lady, who was introduced as the Student Support Specialist. We smiled, shook hands and I sat. I immediately began to take out my devices and material. In the process Chris the Compassionate, began with “so you are interviewing today for one of our positions”. I quickly realized that there was a bit of confusion, they were expecting an applicant today and not a research investigator. I informed him that I was the research student and per his directives I scheduled an interview appointment with his secretary who must have thought the interview was employment related. I asked if today would still be a good time and though he inquired the expected timeframe to which I replied 45-60 minutes he assured me it was okay. He sat back and chuckled... while the SSS staff member said, “I’ll let you two work on this”. She and I exchanged pleasantries and after leaving the room for a quick moment, he returned, sat and we proceeded with the interview.

Despite the somewhat awkward start, I quickly realized that in his 25<sup>th</sup> year of Education, Chris the Compassionate was doing exactly what he long desired and always knew he would do. He graduated from Texas Southern University with a major in Elementary Education and a concentration in mathematics. He earned his Administrative Leadership degree from Prairie View A&M University and is currently pursuing a doctorate degree from Lamar University.

He started his early career in 1992 as a fourth grade teacher and taught for

several years at an urban inner city elementary school, where he eventually became an Assistant Principal and then Principal. He spent 14 years at the same campus and eventually moved to the Director of Elementary School at the admin level. After 6 years working in central office district leadership offered Chris the Compassionate the Principals position at the House of Healing he is currently serving. He is in his fourth year.

Chris the Compassionate is the son of a teacher veteran with over 35 years of experience. He explains that, “I was always on a campus, particularly at a high school, because she was a high school teacher, so on the weekends we were there and that had a huge influence on me.” The longer he spoke the more passionate he became and reflected deeply upon his transition into leadership:

Well, it was an easy transition for me because my last year of teaching, the Assistant Principal at that particular time was retiring, and so the Principal relieved me of some my teaching duties to assist her, because she needed help from an administrative position...so since I just graduated from Prairie View with my Master's, and I just recently passed my test, I took on some administrative roles and then I want to say midyear...about the second semester, is when I transitioned to becoming Assistant Principal. The difference I saw was, as a teacher, I had the influence over 22 kids, but as an administrator, I had the influence over several hundred kids, and so...The other thing too was, just dealing with adults, and as a teacher, you're dealing with pretty much just the students and their parents. As an administrator, you're dealing with the teaching staff, regular staff, at the campus, as well as parents and so bringing all that together and keeping the whole team focused was the biggest transition for me...

As we sat in what appeared to be a centralized room for planning and student intervention, it became evident that Chris the Compassionate has maintained his

commitment to education as he contends that it is his job to put the best teachers before the kids. He very confidently conveys that once he is unable to do that he no longer needs to be an administrator. He explains, "...when I interview, select, and hire good teachers, and I can see the impact they're making in the classroom, that's very rewarding for me." Specifically, in regards to students with chronic conditions, he upholds that "...you've got to have a teacher, a special teacher that can address the needs of those particular types of kids, with those issues, because they have to take it personal. ...they have to be willing to address the needs of those kids so for me, it's finding the right teacher, for a good fit."

It all made sense, when asked "what do you feel are some of the significant personal qualities, values, behaviors, necessary for administrators involved in managing the school experience of all students, but specifically students with chronic conditions:

I think first of all, you have to be understanding because as an administrator, all kids are not the same, they all come with various issues, disabilities, and concerns. So you have to be understanding, caring, and you have to be the cheerleader for those kids, because if you're not the cheerleader, you and the teacher must be the cheerleaders, and you have to do what's best... think in the best interest of the kids. If you don't have an administrators that are caring about kids, you have to reflect why did you get into education?

His passion is catapulted by his perception of the educational experience he had. According to him, he, "went into education to make an impact on kids because I felt like hey, I didn't get a good education growing up, and it's like there's some things that I should have learned in elementary that I didn't learn, so I said let me see if I can prevent that from happening." As the first African American Principal at his campus, though

compassion, caring and hiring the right staff are pertinent to his leadership beliefs in regards to caring for students with medical conditions, he is open about the fact that his drive to be successful as a school administrator comes with a chip on his shoulder. He acknowledges that “you’ve got to have an inner drive to succeed and not fail.” Further Chris the Compassionate wholeheartedly expresses that, “...if you are going to be a campus leader, you have to be compassionate and care about all of the kids, regardless of their race, regardless of their learning ability, and whatever types of disabilities that they have”.

## ***Interview 2***

***Meet Eve the Exuberant.*** Named for her contagious energy and excitement for community and collaboration, she offers just the right dose of exuberance as a leader. Journey with me as I visit her house of healing.

After having to push the original appointment time back by a few hours the night before due to a last minute offsite appointment, Eve the Exuberant exuded an energy via email that made me excited to visit the campus. There was a bit of conflict as I feared that it would run into another prescheduled research interview; but with sheer certainty she promised to arrive to the school in time to complete the interview. Her assurance and direct communication was greatly appreciated, particularly given my appreciation for the commitment of time each participant displayed.

Upon arriving to the campus and walking into the check in lobby, I was drawn to two signs that immediately set the tone for the type of culture that the administrator and House of Healing (campus) embodied. The first sign read, “AT OUR SCHOOL

PARENTS ARE IMPORTANT” which hung just outside the glass doors that protected the staff and students from the general public. To the left upon entering was a sliding window where I provided the necessary documentation to check in. On the wall to the left of the sign-in window was a strikingly profound poster with students donning high school graduation caps and gowns that read “We graduated...And So Can You”. What amazing visual I thought! What a connection to the community!

As each staff member passed, they affectionately extended greetings as they sported holiday attire. I chuckled for a brief moment and appreciated that these interviews were being conducted during such joyous time of the year. I was offered a seat in the lobby as I awaited to be called to speak with who I would come to refer to as Eve the Exuberant. It gave me time to take in the freshness of the school and the beaming sunlight that filled the front hallways as the rays burst through the glass entrance of the school. A “*Think Exemplary*” sign also hung on the school wall. I really reflected on the architecture of the school as compared to the previous site. There was really this exuberant presence that I would later realize is certainly reflected in the personality of its leader.

Eventually, I was greeted with a smile by a staff member who led me directly across the hall into the administrative suites. We entered an open space that had clearly housed a staff party of some sort as the room was filled with treats that was enticing, though I declined a very kind offering to indulge. My anticipation of the meeting would not let me enjoy but the spirit of the room was comparable to that which was evident upon entering this house of healing. As we veered left down a very short hallway, I was

quickly drawn to a young lady wearing a beautiful hot pink blouse sitting at her desk.

She waved me into the office and immediately extended her hand and offered a vibrant “hi”. We sat at a table that gave the office a very warm feeling to accompany a few wall pieces that also gave the office the feeling of home. After reviewing the consents, we jumped right into our very energetic conversation.

Eve the Exuberant is in her third year at her house of healing. Prior to, she was an Associate Principal for one year at what was a dual campus located just down the street from her current location. That campus was particularly unique as she helped lead two campuses located across the street from one another. During her tenure at the dual campuses one leadership team managed both schools; however that has since changed.

Today, she explained that two separate administrative teams operate the campuses. Prior to that, she was an assistant principal for 3 years, a testing coordinator, a teacher with most of her professional experience, 12 years to be exact, in her current district.

As Eve the Exuberant shared her educational background, I found myself smiling as her high energy was contagious. She explained:

Yes, I attended University of Houston, and I graduated with a B.A. in Business Management, and then I became alternatively certified to teach, and I taught math at [another school]. Then I got my Master’s from Prairie View in 2006, and now I’m currently working on my doctorate with Sam Houston in Ed. Leadership.

With five years of elementary teaching experience prior to transitioning into leadership, Eve the Exuberant expressed an infinity for working with low income, high economically disadvantaged populations. In discussing her transition to being an

administrator in an urban environment or urban city specifically, she expressed that:

I prefer to work in this environment, because I like just being connected to the community and helping in so many different ways, even beyond educating the child. There's so many other aspects of the job as an administrator and in this type of setting, you have to have those skills as well, and be able to support parents...parents who are maybe uneducated...

Eve the Exuberant relies heavily on her personality to connect with her school community and the populations in which she serves. She spoke often of her desire to impact more than just a classroom of students. It is important to her to invite the community in and she understand unequivocally that she as the leader "can create the culture for the entire school, which directly impacts our community". This belief transcends her ideals regarding significant personal qualities, values, and behaviors necessary for administrators in managing the school experience of students with chronic conditions:

I think you have to be open-minded, patient, and willing to learn something new, because if I don't have anyone in my family, immediate family with a chronic illness, I don't deal with it every day.

Further, Eve the Exuberant asserts that you have to understand where they (students and their families) are. When you understand where they are, as a leader, she's able to be patient, understanding, and non-judgmental.

### ***Interview 3***

**Meet Daniel the Disciplined.** His name was influenced by the structured mandates of his father and his 20 plus years of experience in the service. He provides a dose of discipline and order to his campus. Journey with me as I visit his house of

healing.

It was the holiday season and as I approached the third school during this research process, I appreciated the flow of parents that was entering the school in the early afternoon hours. Just as the previous schools were set up, I entered through glass doors of an older building and immediately took notice of the sitting area. It registered during this visit that this particular district had an established tradition regarding school décor. The sitting area gave rise to a down home southern atmosphere with comfortable sitting chairs, couches, end tables and a framed Texas flag. It really was reminiscent of your southern country home that served as the cornerstone of family gatherings. I noticed a women, who I would later learn was a parent, sitting in one of the sitting areas with high back chairs. They were very similar to any decorative chair you would find in a home. A Christmas tree to my left contributed to a very welcoming atmosphere and complemented the family friendly environment that clearly seemed deliberate.

I approached the opening in a glass window that shut the lobby off to the front office and was greeted by a staff member. After following the protocol of swiping my license through the system and her handing me an ID sticker, she let me know that Daniel the Disciplined would be up to greet me shortly. In the meantime, I took a moment to look as I'd done during my previous visits at posters, signs, and pictures that may tell me more about the parents or populations the school served. In this case, the school advertised a Kola Care poster for child care and a Penguin Peach Kids Holiday Shop event. Posted on the window was of the office was a sign detailing school visitor policies and procedures.

As I was waiting, a well-groomed staff member carrying a walkie talkie approached the lobby along with a staff member who was dressed as the Grinch, for holiday purposes I'm certain, greeted the parent waiting in the lobby. It was a friendly greeting and as they left the lobby, I couldn't help but notice a group of students rehearsing for a holiday performance. The students were singing "We Wish You a Merry Christmas"; which ironically complimented several parents who entered the building to deliver party items for their child's class. Other teachers who walked pass the front office sported their holiday attire and carried warm smiles as they greeted one another in the halls.

Eventually, I was received by a well-groomed man with glasses who addressed me with an enormous smile. As we walked through the office, into a conference room near the front he jokingly stated, "you know your middle name Cne' is the reason I responded to your email...we have an assistant principal whose name is Cne". I was gracious and shocked but it certainly set the tone for an easy interview.

Daniel the Disciplined was perhaps the most unique administrator, as he is a self-described late educator. Daniel the Disciplined earned his first Bachelors of Arts degree in Psychology from the University of Maryland. He explained that "if you did an art, you had to do a language, and my language was actually Japanese". After explaining that he took 12 semesters of Japanese, he joked, "but don't ask me to say anything in Japanese...as it was so long ago". While in the Marine Corps, he completed a Masters in Elementary Education from Wheelock College in Boston, Massachusetts through base site classes. After pursuing a certificate of an advanced graduate degree he earned a

certification in administration at Cambridge College. Most recently, he completed his Ed.D. in August. He's a fifth year principal with over 10 years of experience as an educator. He explained:

I was a marine for twenty-three years, retired, and decided I wanted to do education. So this is my fifteenth year, I started in South Carolina teaching first grade, right out of the Marine Corps...that was quite a deal. I came here about ten years ago, this is my eleventh year in the district and I've taught several elementary grades, been an AP and then Principal...right here in the district.

It was quickly evident that he truly valued his responsibilities as a school leader.

He shared his reflective take on his transition to being a school leader:

One of the things I realized though, coming into administration is, a lot of what you learn and do is depended on what the school needed most at the time. Like for me it was always making sure that the management of the school in terms of student management, teacher management, all of that was organized and in place. Like you would organize your classroom, making sure that you have good systems and procedures in the school.

In saying this, he is keenly aware that his role as a leader is driven most dominantly by having the opportunity to shape the lives of kids, students and teachers. He understands that what he does as a leader impacts everyone in the school building.

#### ***Interview 4***

**Meet Shane the Servant.** He encourages his staff to lead with a heart of service and administers his own dose of servitude to his house of healing daily. Journey with me as we visit his house of healing.

Approaching what I knew was likely the final interview in this research process,

I was thoughtful of the previous three participants. The weather offered a sense of calmness, as the sun gave a gentle presence. Approximately 50 minutes from my initial destination, the school was like most of the other schools in the district that sat within an older heavily wooded neighborhood. Though the landscaping was dated, I smiled at the marquee board. It was uniquely designed with a giant ruler, pencil and color serving as the foundation for the actual message board. It certainly said welcome to our elementary school. One of the custodians was providing maintenance to the schools entrance. I arrived 30 minutes prior to the scheduled interview time, so I had a moment to recollect statements from previous interviews.

Upon entering the building, my attention was immediately drawn to a wall adorned with student photographs. I Checked in with the front office staff as normal and after I was directed, took a seat at a table directly across from the office check in window. In front of me was television which as it had done in previous schools displayed scrolling news. The screen highlighted student of the month profiles and photographs from grandparents' day. As I was awaiting, I noticed a radiant professional approach a family of 4 (2 adults and 2 children). He introduced himself as the school principal and offered the most confirming greeting to the young student who would be starting school the following Monday. He high fived the students and confirmed to the parents that they would be okay. Following this conversation he acknowledged me with a friendly, "Mrs. Hayes".

As I followed him through the main office, he informed a staff member via walkie talkie that he would report to small group sessions in the afternoon. We ran into

two additional staff members that reported success with turning in testing material at the district office this morning, as the school had just wrapped up state testing. I quickly gathered that this was indeed an environment that celebrated team success. Shane the Servant, congratulated them on a job well done and informed them that they would talk later. The communication between the staff was not only respectful but I got this enormous sense that it was genuine and sincere. I clearly noted that he was not only a leader but extraordinarily engaged.

Upon entering his office he offered an apology for the crowded office that housed a book case with student level books, board games, student workbooks and other student friendly material. Immediately my initial impression was validated, as this was clearly more than just an office that was utilized for an administrator but for someone who was involved in day to day interactions with students.

Shane the Servant considers himself to be a servant centered leader who graduated from Southern University in Baton Rouge, LA. He carries great pride in communicating that he earned his Bachelors degree in elementary and middle school math and science. His early career began as a teacher at Southern University Laboratory School. He recalls, "I felt like it was an honor because normally you're not hired without a Masters Degree, but because I did my student teaching there and the principal saw me teach, she knew that I had aspirations to get my Masters right away...she said I know you're going to get your Masters, if you're interested in a position, I will hire you with the condition that you're enrolling immediately, which I was". He stayed at Southern Lab for 3 years. Eventually, he moved back home to complete 2 additional years of

teaching in Morgan City Parish before being hired as an administrator, where he served for 2 years. With 16 years of leadership experience in another Texas district, he is in his twenty-fifth year within the education field.

When asked to tell me a little about himself, he contends, “For the most part, I consider myself a servant centered leader. I’m all about students, parents, staff, community and I think if you keep that in mind, you really understand the true reason why you’re here and what your role is, and everything that falls under that”. He lives just six minutes away from the campus and was visibly excited to be connected to the community he serves in a leadership capacity.

### **Analysis of Findings**

The following section presents an analysis of the findings as the stories of the participants unfolded. Several themes emerged as the researcher proceeded through interviewing, transcribing and evaluating the data. These major themes, all of which revealed commonalities between the participants are divided into research questions that were answered during this study:

- 1.) How do administrators describe personal characteristics that lead to managing the school experience of chronically ill students in urban schools or communities?
- 2.) How do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities?
- 3.) How do administrators describe their leadership acts related to the academic achievement of chronically ill students within a recognized urban school district?
- 4.) How do administrators describe their leadership acts related to the social

adjustment of chronically ill students?

The following critical themes were identified 1) Increased Power to Impact 2) Lead with a Moral Compass 3) Create an inclusive culture and 4.) Transformational leadership.

***Research Question 1: How do administrators describe personal characteristics that lead to managing the school experience of chronically ill students?***

In addressing research question one, each of the four administrators presented data that reflected a desire to impact and leading with a moral compass. Although there were some challenges discovered during the interview process, each of the participants lead with personal convictions that stemmed from their deep desire to have a lasting impression.

The data also revealed that the participants' moral compass and their personal desire to impact was highly influenced by the subtheme *upbringing*.

### **Increased desire and power to impact**

Critical to the role of school leaders is understanding that there is indeed a shift that occurs in the amount of power your position carries. It is pertinent that a leader understands that their desire to impact moves beyond the specific grade level or content area they were once teaching toward a much more expanded level of influence. Your capacity and ability to impact students with diverse needs and the staff that serve them increases tremendously. In knowing this, leaders should be keenly aware that this transition carries with it a pertinent level of self-awareness and an increased capacity to

impact every subpopulation of students within your school. In this study, each participant describes their transition into leadership has having an increased opportunity to impact.

Chris the Compassionate contends,

The difference that I saw was, as a teacher, I had the influence over 22 kids, but as an administrator, I had the influence of over several hundred kids. The other thing too was, just dealing with adults, because as a teacher you are dealing with pretty much just the students and their parents. As an administrator, you're dealing with the teaching staff, the regular staff at the campus, plus the parents, and so bringing all that together and keeping a whole team focused was the biggest transition for me, because you have so many different levels of diversity.

Eve the Exuberant carried a similar tone, when asked to consider the most appealing aspect of being a school leader,

I think the most appealing aspect for me is that I get to impact more than just a classroom of students, and I think for me, I have a personality where I want to invite the community in, I want to make sure the students are learning, I want to make sure they feel safe and welcome, and ready to learn. I think when I was in the classroom, I was able to create that culture in a classroom, but now as a leader, I can create the culture for the entire school, which directly impacts our community, so I think just a greater impact being a school leader than a classroom teacher.

In regards to being critically aware of ones impact as an administrator generally speaking, Daniel the Disciplined affirms that

By fay, the most appealing aspect is being able to shape the lives of kids, students and teachers and that might sound trite, but I never lose sight of that. That I'm here, and what I do impacts everyone in this building, so I need to do it well, because the kids don't get a second chance always at that particular grade level, serious decisions are made that can impact their future, and then for the adults...making sure that it's an environment where the adults want to be because then I can get the best out of them. So that's kind of where I put my priority.

The impact and influence of serving as a school leader is great and Shane the Servant expressed his awareness of this fact in a less direct but reflective manner. He expressed that for him he is driven daily

...when the students—your former students come back as a high school senior and give you an invitation and say you know what, even though I may only have ten invitations because of the venue, you've made such an impact on my life, so I want you to come to my graduation. That's the biggest reward.

### **Lead with a moral compass**

Each of these leaders embodied a desire to impact their schools and students and expressed understanding of what comes with that. Once school administrators understand the impact of their position and the magnitude of their influence as a leader in managing the entire school; and in the case of this study, specifically those with chronic conditions, it is paramount that leaders embody a sense of moral commitment. Valerie Ooka Pang built a caring centered framework that was first rooted in the work of Carl Rogers and Jerome Freiberg. According to O'Pang, (2001),

They [Rogers and Freiberg] believed that the development of strong caring relationships was key to a foundation for humanistic schools. Elements that they identified were teacher empathy, positive school climate, trusting relationships; they believed these characteristics fostered effective learning environments where students developed high self-esteem confidence, and commitment to personal growth.

As such, a critical component to developing humanistic schools is acknowledging circumstances that require school leaders to manage the educational experiences of students with chronic conditions. These students are real children, with real needs and according to the data collected from the four participants in this study,

school leaders lead with a moral compass in managing their school experiences.

When asked what are some of the significant personal qualities, values, and behaviors necessary for administrators involved in managing the school experience of students with chronic conditions, Daniel the Disciplined replied,

I think you have to care, number one, you have to care. When I say care, I'm not talking about this triteness that people... that I really care about kids. I'm talking about caring to the level where it might be uncomfortable for you, it might cause you to reshape some things at school to accommodate students, so you're thinking to that level. You want to make sure that whatever the student needs, you're going to get it to the students even if it inconveniences you. So you have to have that, you have to have a sense of care...you have to have a sense I think of empathy.

He goes on to explain,

I think my faith, I believe strongly that my faith, I'm a Christian and I fully believe that I've been forgiven, I've been accepted, and I'm not worthy of that. Well that helps me to do those things that I said earlier, it helps me to empathize, it helps me to care and it helps me to have structure, professionalism.

When asked the same question, Chris the Compassionate offered the following discourse,

I think first of all, you have to be understanding because as an administrator, all kids are not the same they all come with various issues, disabilities, concerns. So you have to be understanding, caring, and you have to be the cheerleader for those kids, because if you're not the cheerleader...you and the teacher must be the cheerleaders, and you have to do what's best, think in the best interest of the kids. If you don't have administrators that are caring about kids; with or without chronic conditions, you have to reflect why did you get into education? You have to be compassionate about kids...

Shane the Servant in his explanation of significant personal qualities that he

possess, values that he carries behaviors that he may exhibit that are necessary for administrators in the management of students with chronic conditions confirmed his commitment to being a servant leader.

First of all, we talked about being a servant leader. If everyone understands that you're here for them, if everyone understands that you care for them, you want the best for them it makes all of those situations easier. You have difficult conversations, we call it critical conversations, with staff members, with parents, with students,, but again, if they feel that you truly care for them, if they feel that you're fair and consistent despite their chronic condition, it makes the job easier.

Eve the Exuberant as does the other participants relies heavily on her upbringing and previous experiences to affirm her moral standards in leading her school and managing students with chronic conditions. According to her, because of her experiences,

I'm able to be patient, understanding, and not judgmental...I just try to help them the best way I can and I think I do a pretty good job of meeting them where they are, and then trying to explain to them where we're going to get their child to, so that they don't experience those same challenges that maybe other families have experienced.

She further explains,

I always put myself in the parents' shoes, because I don't have a child with a special need or chronic illness, but is a struggle just to be a parent. I have two kids, one is four and I mean it's a struggle! Even this morning trying to get out of the house with all of the things that he needed for his Christmas party and this and that, and I still went, got in the car and left something. However, if I also had to get a wheelchair, or an oxygen tank, or special foods, because some kids have the feeding tube... I can't even imagine what those parents must go through, and so for me it's always making sure that we're not judging parents or not being quick to...the rules are the rules, and we can't bend them for you.

The influence of school leader's upbringing is an important component to

leading with a caring-centered, reflective or moral compass. Research asserts that past experiences shape our perceptions, beliefs, and values. As educators, specifically school leaders these things in both direct and indirect fashion influences the school culture created, decisions made and interactions with those being served.

Eve the Exuberant further explains that not only is she shaped by her background, upbringing and the range of diversity within her family she remembers an experience with a middle school classmate that continues to impact the manner in which she serves students with chronic conditions.

I remember when I was in middle school, it was a good friend of mine, I can't remember long period of time, because she had lung issues. I think it was respiratory, because I know she was on a breathing machine at certain times. Anyway, I so loved caring for her. I remember this back then, but people would be like, *who's that weird girl in the wheelchair and I'm like I'll push you around.* But over Christmas break she passed away, we were devastated when we got back to school, and we didn't see it coming. That experience just stays with me forever, because I think about our kids and you see them every day and you don't know if you're going to see them tomorrow. Some of them have chronic illnesses, so you have to love on them, love on their families...whatever you can do to support them.

Culture refers to the symbolic meanings by which the members of a society communicate with and understand themselves, each other, and the world around them (Covertino, Levinson, and Norma Gonzalez, 2013, pg. 26). In the sense of understanding the subpopulation of students with chronic conditions and their unique culture, administrators should and will often utilize their understanding of personal experiences to understand their students' world. Dose of Servitude has not only been influenced by his father's role as a school principal but having experienced family members with cancer as well;

Coming from a big extended family, as I said, everyone as far as my mom and dad's siblings, who went to college, they went in education. Then coming from a large extended family, I've had family members who have been diagnosed with cancer. You have to be able to work through students through these experiences and counsel them through, because it carries over into the school when it comes to their motivational levels and really impacting their potential. I've dealt with death...so having those experiences and being able to allow students to see I can relate, allow parents to know that I can relate and in talking about certain experiences that I've had, it just brings that connection even closer to let them know that you're truly here to help them through the crisis, through their situation.

Daniel the Disciplined is also able to reflect upon his upbringing from the perspective of having his father and his environment shape his perspective and approach to leading schools and students with chronic conditions.

My background, coming up, poor kid, South Carolina, just not being able to speak standard English, just all sorts of stuff right, that I dealt with. I'm not unique in that, there are other people, but what I've tried to do is never lose sight of that. It's made me who I am, so it allows me to empathize with my kids, I don't see them as odd, I don't see them as different, I just see them as kids. My dad...we didn't have anything at all, but we had discipline we had order and structure, we had responsibility, all of those things that you just come up with. So for my kids here at school, I know that, I know that for them to be successful, we're going to have to keep them structured, disciplined, and operating in an orderly way.

Similarly, Chris the Compassionate also relates to his mother and her influence on him as a leader.

Well my mom was an educator for over thirty years... that had influence. I was always on campus, particularly at a high school, because she was a high school teacher, so on the weekends we were there, that had a huge influence on me and just watching my high school principal, and how he ran the campus, and how he took the leadership role to ensure that the school was safe.

In regards to his experience with chronic conditions,

I mean we all have family members that have medical conditions, and I remember before my grandmother passed, she had to take insulin shots, I would care for her and give her insulin shots, and as I relate that to this campus level, we have kids here that are on insulin, that have those medical conditions, that are diabetic, and we have to make sure that those kids get their insulin, and if not, something tragic could happen. From a personal perspective, taking care of my grandmother, I see the caring part, taking care of these kids here that are diabetic.

## **Summary**

The participants in this study described personal characteristics that influence their management of the school experience of chronically ill students in urban environments. As the participants described what emerged as major themes, an increased power to impact and lead with moral compass, it quickly became evident that these participants were innately committed to seeing all students within their school succeed, even those with chronic conditions. As these participants understood that their transition into leadership carried with it an increased capacity to impact students, every subpopulation of students that entered the building and in this case an increased capacity to manage the care of students with chronic conditions. These participants understand that their values and upbringing play a significant role in understanding the students they serve and impact the manner in which they serve them.

Further, participants confirmed that leading with an ethical perspective or moral compass affirms a sense of support for students being served, their parents and staff responsible for the direct care of students. It's a perspective that focuses on relationships (Katz, Noddings & Strike, 1999; Noddings, 1984, 1992; Gilligan, 1982) with a foundation to maintain and enhance caring relations. Noddings (1996), refers to this as

“a commitment to receptive attention and a willingness to respond to the helpfully to legitimate needs” (p. 265). Each of the participants articulated that they each understand that characteristics such as care, empathy, compassion, and open-mindedness are imperative in meeting the legitimate needs of students with chronic conditions within their schools.

In the next the next section, I present the participants perspective on how administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities.

***Research Question 2: How do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities?***

When exercising and interpreting their acts in the educational management of chronically ill students within urban communities multiple subthemes evolved: hiring the right staff, training staff, and effective communication. From these subthemes the major theme, “Managing the Process” evolved.

### **Creative and Inclusive Culture**

The basis of this research question, was established to gain an understanding of how administrators perceived the capacity of their role in managing the school experience of students with chronic health conditions. What should they be doing, what are they doing and how do they interpret these acts? Daniel the Disciplined provided perhaps the most concise and direct articulation. He replied,

Oversight, and let me describe oversight as making sure the right people to service the students are in place. Making sure that the services are appropriate, not just through the hiring process, but just making sure that everything is orderly, and being able to assign people to make sure that that happens. So ultimately having oversight over all of that.

Apart of managing the process is being able to set forth a vision and establishing a culture within the school that is committed to moving the vision forward. Eve the Exuberant explains that a successful technique she has relied upon in successfully managing students with chronic conditions is being proactive,

...definitely having a plan in place, practicing, even if a child doesn't have an episode over the first semester, going back to revisit that plan midway through theyear to say, "do you guys all remember what we were supposed to do?" And then if we have any personnel changes, making sure they're aware of the plan.

She also affirms that as an administrator she is responsible for setting the vision of where she wants her campus to be, so it's necessary to be a visionary leader in managing the students with chronic conditions.

...being astute and being able to understand what's happening around you, when it's happening, and not after you get some kind of feedback or scores or whatever, but being aware of what's taking place in the moment with these students, especially those with chronic conditions and being bold and not afraid to make adjustments.

Shane the Servant illustrates how he interprets the act of managing the process,

The best part is when all of the systems are in place whatever the condition is, it can be managed without your input or intervention. Be it an allergy--- everyone knows, and I'm not talking about just the family and teacher. I mean everybody in the learning environment. They may not know the specific crisis or situation that is aligned to the respective student, but if they

know that this is a peanut free zone because this allergy is a part of our classroom community, then the class knows what need to happen to make sure that everybody is able to learn in a comfortable environment. That's one of our school rules, it's all a part of our mission, vision; being able to come and learn in a comfortable and respectful environment. So has an administrator you may not have to intervene because all of those things are in place...having all of it to operate like a well-oiled machine.

### **Hiring and Training the Right Staff**

In managing the process, three of the participants spoke directly to administrator's obligation to hire the right staff and or addressed the difficulties in finding properly trained staff to hire. Personnel was communicated as a primary responsibility of administrators. Chris the Compassionate, contends "...as an administrator, my job is to make sure I provide the best teachers...that I put the best teachers before the kids. And if I can't put the best teachers before the kids, I don't need to be the administrator."

He reflected,

Well, those issues with a kid that has a chronic medical condition, the key thing is, you have to have the right teachers. A lot of teachers can't work with kids with certain issues, because they have to take it personal. You've got to have teachers who are willing to do anything, they have to be willing to address the needs of those kids, so for me, it's finding the right teacher, for a good fit. I refuse to hire teachers that just couldn't find a job somewhere else just to fill a position. I've waited and waited until I've found the right person to work with kids with special needs.

Though the importance of hiring appropriate staff is widely known, it does not negate the difficulty that is often associated with administrators finding the right staff. It is certainly a critical call to action for administrators, however; research confirms that

one of two critical areas that must receive high leadership attention is that, “principals must develop, enhance, and monitor the professional skills and knowledge of their faculty” (DiPaola, Tschannen-Morna, & Walther-Thomas, 2004). Daniel the Disciplined explains that when addressing obstacles surrounding managing students with chronic conditions;

The personnel, definitely have to have...I mean that's number one. If the kids need specificity, either delivery of the instructions, being able to access the instructions, whatever they need if a person is required to do that, and it can't be done without an additional trained person, then as an administrator sometimes that difficult.

Eve the Exuberant offers, a similar explanation,

Sometimes finding staff who are properly trained and have a mindset and belief that I have, because I feel that we can educate any child that enters this building can be difficult. However, that may be what someone might say to get a job, but then when they're faced with having to do the job, the responsibilities that may come along with the student, then they may not be all that comfortable with it. I don't hire anyone without you going into the classroom and we want to observe you interact with the students.

In this same regard, Chris the Compassionate reinforced,

I think the administrator should play a very key role in the interview process, selecting teachers, and I think that's key. You have good teachers, they should be aware of the medical conditions, because if a kid has something...the worst thing for an administrator, you don't want any kid, to have a death on campus, so you should be aware of all the medical conditions, all of the needs and services for that kid, so they can make sure they're being met.

In addition to addressing the issue of hiring qualified staff, leaders are expected to not only engage in training but ensure that their school personnel received appropriate training. It is evident that training is important in serving all students, but research has

articulated that training for administrators is limited in regards to support received from the central administrative office. Data in this study supports this claim as participants confirmed that they had not received any district level training in the area of medical conditions or serving students who live with them.

Daniel the Disciplined in response to what trainings, have you received as a school administrator, relevant to managing students with chronic conditions, replied, “Chronic, medical conditions? I don’t know that I’ve gotten any, no, I haven’t. Interesting!” Similarly, Eve the Exuberant confirmed, “I can’t think of any. Managing students with chronic conditions.” Chris the Compassionate responded, “Well I haven’t per se had the training, but my staff have”.

Shane the Servant replied similarly but did reflect on previous training received within another district as a new administrator, where they meet once a month to cover a topic that was related being a Principal.

So you cover everything from dealing with kids with chronic illnesses, you dealt with instructional trainings, instructional technology in the classroom just a wealth. So after three years of trainings as an assistant principal or principal, you for the most part were able to fly.

### ***Managing Communication***

Eve the Exuberant also explains that when managing the process, “communication is vital and includes bringing the right team together and discussing what their needs are, and keeping the flow of communication open with their providers, whether it be their parents or the hospital”. In that same regards, Chris the

Compassionate, insists that as a leader he is also responsible for making certain that communication to parents goes out in a timely manner. He also upholds the importance of managing effective communication within the school among staff charged with serving students with chronic conditions.

It's important that you're an effective communicator. I know for me you have to communicate, because if you don't, if not, it brings doubt. Being an effective communicator creates transparency. When you have people, especially adults, and you have a diverse staff, you have to be very transparent, so people can have trust in what you're doing. Without trust, you can't bring about change and for me to bring about change, there is a certain way you treat people. If you talk to people inappropriately you are not going to get that trust or bring about change.

When communication systems are broken within the school as it relates to serving students with chronic conditions, Shane the Servant believes in utilizing a coaching method to have crucial conversations about what worked or didn't work.

Why do you think the system failed, or why do you think this happened, can you give me your opinion, your feedback, your input and let them speak to it and hopefully they already have an idea? If not, I still try to coach again, so they can actually understand what the concern is, and hopefully, based upon that with the coaching process, come up with a solution of how we're going to make it better or what we're going to do the next time we experience a similar situation, and once we finish that conversation, make sure we have a summation.

Overall, Shane the Servant, believes in open communication or transparent communication between staff, students, and parents be it verbal or written.

Something that we started this year too, we started a PTO newsletter, so not only are you getting things from the school aspect, but even in the PTO newsletter that we started this year, I have a spot so I can focus on other things, maybe more from the social side of things, or the emotional side of things, or just with that homeschool connection.

## Summary

According to Volt and Collins (2010), education leaders play a substantial role in the development of inclusive, diverse and standard based roles. They assert that administrators provide the vision and leadership imperative to meeting the needs of diverse students. In this section participants validated that school leaders are and should be drivers in the process of managing students with chronic conditions in the urban school setting. Participants in this study addressed the research question, *how do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities?* The data revealed the evolution of the major theme **managing the process** with two subthemes hiring and training staff, and effective communication.

*Research Question #3- How administrators describe their leadership acts related to the academic achievement of chronically ill students within a recognized urban school district.*

There is no question that school leaders are perpetually forced to embrace far-reaching and extensive, sets of academic school reform mandates despite the varying degrees of diversity represented among the students they serve (DiPaola, Walther-Thomas; 2003, Thurlow, 2000). Undoubtedly, instructional leadership serves as an imperative responsibility for school administrators with student academic achievement being highly scrutinized. Participants in this study acknowledged their role as instructional leaders and described their current acts in ensuring the academic

achievement of students with chronic conditions. In regards to being an instructional leader responsible for the implementation of programs and process, leaders must also understand the laws and federal mandates that protect students with chronic conditions. Data presented below that administrators were aware of federal laws and distinguished how each law was considered in the management of their students with chronic conditions.

Eve the Exuberant explains that his most important responsibility is instruction. He went on to contend,

My leadership style is instruction. As an urban administrator, you have to be strong in instruction, because as an administrator, you have to be able to coach the teachers on strategies, and if you have a first year teacher just come out of college, or a teacher that's coming through an alternative certification program, straight off the streets, that have no experience, it's up to the administrator to guide them, or find someone that can guide them, so that they can learn instructional strategies.

Eve the Exuberant that her approach to academic achievement begins with setting a schoolwide standard of eighty percent. When asked if she maintains this standard for students with chronic conditions she responds immediately "absolutely"; however, within reason and given all pertinent factors

One of my biggest concerns is probably having trying to convince the teacher that as long as a child is showing growth, because I'm very big on students performing well academically. That's 80%, they need to be at 80%, and if a teacher comes and expresses to me that the child is three grade levels behind, how am I going to get her to 80% on grade level? And part of that is just having the whole team together, understanding what their medical needs are, and then how that'll impact their academic needs, and then having clear communication with the parents, and even if they are in the special education program, coming

together with the ARD committee, and determining what's appropriate for their level, where are they now, and where we want them to be in the setting goals for the following year.

that To ensure academic achievement in his school, Daniel the Disciplined contends

It's first through the ARD process and determining what's best for the kids, and then just making sure that all of that is carried out. My special education team leader knows all the kids and their needs, and she's also a go to person whenever there are questions or concerns, or a lack of understanding in how to deal with a certain student.

In regards to students with chronic conditions who are not covered under special education, he explains,

We have students, most of them are probably under 504. I think it's similar, we have a student support specialist who becomes a case manager for those kids, so she meets with the teachers, schedules meetings, and the teachers are able to give updates or to adjust the services that those kids get. That's how we keep track of those students, making sure that they get what they need to be successful.

Shane the Servant provides similar insight, regarding his acts related to the academic achievement of chronically ill students,

Usually their services fall under 504---initially our 504 committee, because we have the school support specialist, we have the respective teachers, the nurse, the parents, and an administrator, the assistant Principle and myself are always there. So you have that entire team, it could fall under the special education team , if it's truly a special education student and a medical condition, disability, what have you, it's pretty much the same thing. You can't be special education and 504 at the same time, so even though you have your two different umbrellas, the team is really the same. Whereas the school support specialist is one who leads the 504 meeting.

Eve the Exuberant also explains that on her campus, that as the school leader she

monitors the process of ensuring academic success but identifies what this looks like

We look at assessments of course, we look at formal and informal data, because it's not always just the state test or that Friday assessment, but just things kids are doing throughout the day, taking anecdotal notes, and determining what their needs are. I don't do it alone, we assemble a team and review all of our data, we call it our needs assessment team, and we typically do it in May, so that we can gear up over the summer, and send teachers to trainings that they need to go to, look at different trends, and then we implement and we monitor and adjust throughout the year. Even though we put somethings in place, if they're not working, we'll make an adjustment and that's for all students, including those with chronic medical conditions.

### **Supporting Academic Achievement following Homebound Placement**

A significant piece of managing the academic achievement of students with chronic conditions also includes the process of transitioning students back onto campus following the need for academic support via homebound programming. Despite limited but existing research suggesting the benefit of comprehensive school re-entry models to support the academic achievement of students transitioning back onto campus, data collected in this study suggest, administrators are either not identifying their processes as a purposeful model or not relying on a comprehensive model to support academic achievement during the transition. When asked if he has implemented a school re-entry model Daniel the Disciplined reports,

We don't in fact, I'm thinking of a student as you said that, who was out on chemotherapy treatment. Yeah you know what, that's probably an area we need to...because we don't think that way, it's kind of like we're back.

Chris the Compassionate also suggested,

I wouldn't personally say it's a model, but there is a process that pretty much all schools have. If you have a kid with a medical condition coming back to campus, and if they are special education, then of course you have an ARD meeting, then of course the nurse, the counselor, they're involved with that process to make sure that we meet the needs of the student. I wouldn't personally say it's a model, but it's a process where if they are in special education, there's an ARD meeting...an ARD meeting to make sure that we meet the needs of the kids, and then the health training, with the teacher, the nurse, and then the counselor.

Eve the Exuberant explains how academic achievement is managed when homebound is necessary and once students are transferred back to campus,

Parents will submit paperwork to that program as well, because we have one student who is in the third grade, who is now a homebound student, and the district has reached out to us to send a find a teacher to go and support that child. So we have a teacher who now goes to the house, and eventually, hopefully, the child will be coming back to school, so then they'll go through some process to inform the district that they're released to come back, and then we have a conference with them, talk to the parent, review the information, and then find out what will be the plan then. Sometimes when they do come back, and there are certain conditions that we need to follow or support them.

When asked to expound upon that process of homebound process and how this supports the students learning she replied,

Typically there are homebound teachers that are hired as a homebound teacher, we'll have to go to the house and support the child, but I think it's because the student started in the school and is expected to return that instead of hiring someone just for this short period of time, which might be difficult to find...that I'm assuming it was beneficial to just get someone from the campus and pay them supplemental pay. But for a student here, if a teacher were to leave campus and go support a child, I feel like they are able to speak the same language. They know the curriculum, they know the teachers. So for our third grade student, the teacher who is going to their house is a fourth grade teacher...so it's awesome because next year, I can put that child in her class, they already have a relationship with the child, their parent, you know their condition, so if anything were to occur, you're prepared, you already know, so I think it's just beneficial all around.

In explaining how he manages the transition Shane the Servant responds,

Those transitions involve the appropriate personnel. Of course nurse, counselor, teachers. If they're going on homebound, of course a homebound teacher is in close contact with the regular classroom teachers, so they can make sure that they're on the right target. They share activities, lessons, so that hopefully, when the student returns, we don't have any gaps...that the students can make a smooth transition right back into the learning environment. I have worked with situations where students were terminal, so homebound services really depended upon how the student was feeling at that respective time. So again, we just try to do as much as possible.

***Research Question #4- How do administrators describe their leadership acts related to the social adjustment of chronically ill students?***

One of the most important aspects of understanding the social adjustments students may undergo is first understanding chronic conditions. Daniel the Disciplined explains the importance of knowledge...”in terms of making sure that people understand, acceptance, because you have to have an environment where kids’ disabilities to that extent are accepted, otherwise it can be really tough for them”. He also explains what it details factors involved in the social adjustment of students with chronic conditions,

Socially, you need to know that kids are okay. Kids embrace kids relatively easily, especially kids who have obvious disabilities, usually kids are okay, and usually kids are really sympathetic towards them. It's making sure that adults are that way, making sure that the adults don't see the kids as a hindrance, or getting in the way. When you have programs, that's a social part of a student's life, and we want students who have chronic conditions and disabilities to be a part of the program and we do that.

Research contends that many social issues derive from the home or community

environment, especially within urban communities. One concern that Eve the Exuberant carries rest in the economic issues that families experience.

Sometimes parents may not have funds, or maybe they get support from the government in some kind of welfare, but don't use funds appropriately to purchase what the child needs. We have students with chronic asthma, they come to school, they don't have a pump, the pump is out, and the parents don't see the importance or urgency to go get it refilled. I can't go...I've tried.

In the instance that something did occur she spoke of having to go to CVS and try to get some strips for the diabetic machine, because the parent didn't make sure that the child had it and blew up on her when she called. When faced with these challenges and understanding the impact these situations have on the social adjustment of the child, Eve the Exuberant says that as a leader she is often "explaining to teachers, that our job, our role is to do everything we can. Not some things, we can't just pick and choose, but we must do it all."

Long term effects of many chronic conditions may result in extraordinary discipline problems that the student may or may not be able to control. Once schools work with the team, parents and medical professionals to determine the root cause, Chris the Compassionate discusses the an intervention tier strategy that he implemented to address behavior concerns,

We have intervention processes, we tier the kids. If you are tier one, you're pretty good kid, tier two means that we're look at you, have some concerns, two or three is very severe. We need to do something about it to help you.

Shane the Servant speaks of a multi-staff approach that enlist crucial staff to support students' social adjustment. Similar research purports that the roles of

counselors and teachers are critical.

The leadership team is a part of welcoming students back on to campus or in general. The counselor pulls them in and lets them know that if they have any concerns, if they need additional support, if they need to talk to her about any challenges, to let her know. Of course the teachers do the same thing one on one, but again, it's just being servant leaders. There's not a model or name for it, it's just what we do.

Across all participants the team also spoke of community partners such as churches, national meals programs and the utilization of the district CYS worker to help support students with medical needs. Specifically, Chris the Compassionate says that "the CYS worker is responsible for contacting outside agencies and identifying outside resources to help kids".

## **Summary**

This study examined and interpreted the experiences and practices of four school administrators in an urban school district. Each of the participants recognized the impact of their upbringing in relation to the moral compass that guides their management of students with chronic conditions in the school environment. The participants recognized their impact extended to all students within the school and thus, confirmed their direct engagement in managing students with chronic conditions. Participants as reflective leaders, also identified areas of challenges and areas of improvement that would help move the district forward in better servicing students with chronic conditions.

## **CHAPTER V**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **Summary**

The experiences of four school administrators within one selected urban district was studied to gain insight into the management of students with chronic health conditions in schools. This qualitative study utilized an inductive and interpretive analysis after conducting in-depth interviews to construct meanings of personal and professional acts relating to the academic achievement, social adjustment and overall management of students with chronic health conditions. The study offers a valuable opportunity to analyze administrators' knowledge, their perceptions and their roles in overseeing the experiences of this unique group of students. In analyzing the multiple realities of these administrators, researchers worked to construct meanings of their personal characteristics, professional acts as it relates to the educational management of students with chronic conditions in their schools; as well as their acts in regards to the academic achievement and social adjustments of these students.

This study lends itself to great significance, as it provides extraordinary insight into the way students with chronic health conditions are being managed in the school environment and to address gaps in creating school cultures conducive to the success of an extremely vulnerable population of students. It provides a framework for best practices for not only school administrators, district administrators and school policy makers, but the data has implications for medical professionals, parents and other multidisciplinary professionals serving these students. This study was conducted to ignite a critical conversation for a

small but important population of students whose services are primarily managed by two common pieces of federal mandates, IDEA and the 504 Rehabilitation Act.

In an attempt to understand the processes by which administrators are currently managing these students via their leadership practices, this study commenced with these research questions as a guide:

- 1.) How do administrators describe personal characteristics that lead to managing the school experience of chronically ill students within urban schools or school district?
- 2.) How do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communicates.
- 3.) How do administrators' describe leadership acts related to the academic achievement of chronically ill students within a recognized urban school district?
- 4.) How do administrators' describe their leadership acts related to the social adjustment of chronically ill students within a recognized urban school district?

As a result of relying on audio-taped recordings from semi-structured interviews with open-ended questions, recorded field notes, non-verbal cues, and observations I was able to investigate the perceptions of these four administrators. As the data was transcribed I was able to identify and develop categories that evolved by comparing the responses of each participants.

The study revealed that administrators perceive that they have established a culture conducive to impacting the school experiences of students with chronic health conditions; however, they each recognized that they are not following any identified framework or

processes specifically established to manage students either diagnosed with a chronic health condition or currently living with a chronic health condition. The stories of these urban administrators have been heard, their acts and perceptions have been documented and recommendations and implications for future studies will follow.

### **Discussion**

During the course of this study, I examined the literature that I conceptualized as relevant to this study. I initially investigated the Ethics of Care theory as a foundational framework but expanded the framework to include a multicultural caring centered approach. Further, I assessed the historical evolution of critical legislation that impacts school administrator's ability to manage students with chronic medical conditions, common medical conditions found among urban school age youth, and, the role of school leaders through a caring centered multicultural lens, and examined studies and literature that analyzed school-reentry models for serving students with chronic conditions. The literature review also reviewed the small body of information regarding homebound school services.

Literature revealed that students with chronic conditions often experience increased psychosocial issues, decreased academic achievement, and frequent absenteeism (Boonen & Petry, 2011; Martinez & Ercikan, 2009; Shaw & Paez, 2002; Vance & Eiser, 2002,). Though scarce, the research also identified educators concerns for servicing students with medical conditions due to lack of knowledge and access to appropriate training. Essentially literature contended that both school leaders and educators largely revealed inadequate experience in dealing with students with special needs (Moore et al., 2009; Vance & Eiser, 2002).

A review of literature also explored the implications of school reentry models and their impact on the experience of students with chronic conditions (Moore et al., 2009; Kaffernberger, 2006). Being that previous research also highlighted school administrators as instructional leaders, I asserted that school administrators not only play an integral role in the facilitation of school re-entry models focusing on students with chronic conditions. There is a lack of research about the school principals or administrators role in the facilitation of school re-entry specifically.

The complexity of managing school age students with chronic conditions is a broadening concern for researchers, educational leaders and medical professionals. Emerging researchers are continuing to identify models for practices when serving urban students with life limiting health conditions. The literature review revealed that district and school leaders should implement research based frameworks to help support the increasing number of students in schools impacted by chronic health conditions. Data collected in this research substantiates that while some activities are conducted on campuses for students with chronic health conditions, programming should be an intentional effort designed to create a transformational multi-cultural caring centered model facilitated by school leaders supporting chronically ill students.

Research calls for leaders to implement a model that addresses the educational medical and social needs of students with chronic health conditions. In doing so, school leaders can ascertain that the needs of students with chronic conditions are managed effectively in the school environment, while leaders are directly working to build critically conscious multicultural morally driven school leaders. Despite, some research targeting the

hospital to school transition for students with chronic conditions, there is small pocket of literature that provides school leaders with a responsive and effective model in managing school age students with inconsistent attendance and their transition following homebound placements (Shaw & McCabe, 2008; Shaw & Brown, 2006).

Data collected in this study confirmed that school personnel should engage in knowledge building, self-reflective policy analysis and the building of a service delivery model. Ultimately, as was the intent of this study, leaders need to work to achieve the consistent integration of a culture of care for students with chronic conditions at the school and district level; while also increasing the efficacy of school personnel charged with implementing the critical care plans of these students.

Both literature review and data from this study determined that school and district level leaders should engage in the process of identifying students with chronic health conditions. While, it is assumed that school nurses are aware of all conditions within the school, this is not always the case and is particularly important in instances when schools are not afforded nursing personnel. As such, school nurses acknowledged that students with chronic conditions need more assistance than they could offer alone (Thies & McAllister, 2001). In order to effectively develop intensive collaboration at the school or district level it is imperative that school leaders have an knowledge of the level of health conditions that exist within the urban school environment and that school administrators are readily involved with leading the process (Thies & McAllister, 2001).

**Research Question #1- How do administrators describe personal characteristics that lead to managing the school experience of chronically ill**

### **students within urban schools or school districts?**

The characteristics and attributes of principal's or school administrators regarding their role in managing schools who care for students with chronic conditions is important. Cindy Praisner (2003) confirms that care must be taken to establish inclusive settings, as such Principals attitudes, their characteristics and perceptions toward serving students with special needs, including those with chronic medical conditions is imperative.

Generally speaking, Praisner (2003) also confirmed that administrator's attitude is generally positive toward creating inclusive climates. The findings in this study support the literature in this regard.

Personal characteristics that emerged within this study include desire to and awareness of an increased power to impact, and lead with a moral compass. Each of these administrators were reflective school leaders who embodied a concern for impacting every student on campus. They were keenly aware of their previous responsibilities as educators and were able to express the contrast between their current roles as administrators. In doing so, each of the participants spoke of impact and being responsible for the entire school community. In this case, the community specifically targets students with chronic conditions.

Chris the Compassionate spoke of the different levels of diversity that has to be managed within the school. Eve the Exuberant reflected on having the personality to invite the whole community and possessing the opportunity to be a greater impact as a school leader than a classroom teacher. I found each of these things to be categorical true as it is paramount that school leaders, at any stage of their tenure are acutely aware, knowledgeable

and committed to serving even the most vulnerable populations, in this case students with chronic conditions within the school successfully.

As administrators acknowledge their expanded influence and impact, this study describe their personal characteristics related to managing the school experience of chronically ill students as morally driven. They each expressed that administrators must care first and far most. This includes caring enough to ascertain that each student with a medical condition are viewed just as any other student on the campus is being viewed; however, that their diagnosis and its implications are always taken into account to ensure the best possible learning opportunities.

Each of these participants were able to highlight significant moments in their upbringing that has undoubtedly impacted their approach to leadership and their commitment to leading with a moral or caring approach. They spoke of understanding the needs of these students and often times connected their approach to personal experiences with medical conditions. At the plight of managing these students is an invaluable characteristic to care which ultimately impacts the culture of the school and the environment in which these students are expected to thrive.

**Research Question #2: How do administrators exercise and interpret their acts in the educational management of chronically ill students within urban communities?**

Notably, Paul McCabe has also contributed significantly to research regarding pediatric health issues addressed in schools. As co-editor of *Pediatric Disorders: Current topics and Interventions for Educators* McCabe with a number of colleagues provided an informative and necessary product asserting the implications of various health conditions on

educators (McCabe & Shaw, 2010). He asserts that knowledge of the effects of conditions such as cancer, is vital for educators (McCabe, 2010). His work negates the issue of misinformation and instead offers educators strategies and tools for supporting students and parents in the school environment (Brenner & McCabe, 2010; Lawrence & McCabe, 2010; Racanello & McCabe, 2010).

In direct relationship to my research interest McCabe and his colleague contends that the integration of health care in the school environment is a direct responsibility of administrative leadership (Shaw et al, 2010). As such, the research calls for principals to establish multidisciplinary teams, partner with parents, facilitate collaboration with community, create individualized plans students, train staff, support emotional needs of students and create bereavement plans in the evident it is necessary (Shaw we al, 201). It in this case, is the principal's responsibility to facilitate and lead the charge in the school environment as the catalyst of culture and academic success.

The findings in this study suggest that the perceptions of school administrators align with literature reviewed. Participants in this study interpreted their acts as being overseers who manages the process of meeting the educational and psychosocial needs of students, specifically those with chronic medical conditions. It is their perceived notion that they are responsible for ascertaining that every aspect of managing students with chronic conditions, the programs that serve them, the staff that are responsible for their care and the processes by which they are served is facilitated through them and directly related to the culture they establish within the school. Eve the Exuberant described it as having a vision for your campus and although managing the process was the critical theme that emerged, several

subthemes evolved throughout the study. Hiring and training the right staff and managing effective communication were subthemes that resonated deeply across all participants.

Specifically, Daniel the Disciplined speaks of oversight and recognizes that he can't ask teachers, students or parents to do what he hasn't done or does not understand. He describes the mentoring he received and how it set the standard for operating the way he was taught. He also discussed making the plans to do what is necessary to make sure that a particular student with needs was in the right environment. Administrators being actively engaged in the process of caring for students with medical needs ensures that as they make decisions related to programming, budgets, personnel assignments, trainings etc. the needs of students with medical conditions are being accounted for. It moves beyond the common trend of addressing problems at the point of conflict but rather as a proactive measure given the common trends of medical conditions among urban youth.

One of the most pressing responsibilities of operating schools is hiring staff with the mindset, skill set and will to effectively serve students with great needs. Administrators in this study did perceive that hiring the right staff is a fundamental responsibility of school leaders. As such, they discussed their direct involvement and communicated practices that they currently utilize such as classroom interactions during the interview process as described by Eve the Exuberant. This study did reveal however, that beyond reviewing special education and 504 laws, staff did not readily engage in trainings until a student was identified as having specific needs. For example, Daniel the Disciplined discussed how the effort of caring for students with medical conditions is a team effort and if they have diet restrictions everyone is trained to ensure restrictions are managed and food is prepared

appropriately. His approach to cross training staff in the event one person is out others can go in and support physical or educational needs at any given time is invaluable I believe. On the other hand he did acknowledge that administrators and educators should have knowledge of various disabilities so that you can act rightly and accurately. Research does support these findings as in the case for students with cancer school personnel often feel unprepared to meet the educational and interpersonal needs these students (Prevatt & Lowe, 2000)

Eve the Exuberant also validated the need for improved training at the district and school level that supports a uniform approach for serving students whose educational and medical needs intersect. She discussed district level uniformity upon enrollment of any student with chronic conditions or upon their return to school. What do you do, how do you do it? As presented in the literature review of this presentation, growing research does address school reintegration programs for students with chronic medical conditions to address the long term effects (Canter & Roberts, 2010). I agree that as administrators in the position of overseeing the hiring and training and staff addressing these voiced gaps will only improve the continued advancement of care for students with chronic conditions in schools.

Effective communication under all circumstances begins with messages being disseminated by the school leader on any campus. This study revealed that communication is vital and participants have worked significantly to maintain order across their schools as a result of this belief. From communication with students' medical doctors to overseeing communication models through the assembly of staff directly responsible for servicing

students with chronic conditions, administrators are liable for setting the appropriate stage. As participants expressed their means for maintain communication, it was the voice and story of Shane the Servant that most implied the benefits of open, effective and detailed communication. He discussed that as a result of developing an open communication model one of his parents had prepared him and of course the nurse if the student experienced extreme difficulty breathing after taking his medication to put him in the freezer until she or the ambulance arrived. He recalled having to get in the big freezer in the cafeteria with him because it would help until the paramedics arrived. Given that most people would not know to do that the process of communication was critical.

**Research Question #3: How do administrators describe their leadership acts related to the academic achievement of chronically-ill students within a recognized urban school district?**

The third research question presented in this study allowed researchers the opportunity to validate the deep rooted ideals that school administrators are indeed the most important instructional leader on campus. The literature examined confirmed that principals who focus on instructional issues and provide high-quality professional development for teachers improve academic outcomes for students with special conditions (DiPaola, & Walther-Thomas, 2003; Yovanoff & Harniss, 2001). Recognizing that research directly related to administrators perceptions on the academic achievement of students with chronic conditions is void, data collected in this study determined that principals still considered their role as instructional leaders was paramount to the management of students with chronic conditions, Participants communicated that this is still the case for students with

expressed medical needs. Though it is often highlighted in research regarding administrators and their unpreparedness in special education or 504 laws and or in providing services for students with chronic needs, participants in this study were eager to express that they were instructional leaders first with an impressive amount of knowledge in these laws. Some, like Chris the Compassionate discussed being an excellent instructional leader at the onset of his administrative career, others like Daniel the Disciplined admitted that his role as an effective instructional leader evolved over time. Each of the participants communicated the necessary focus of reducing any academic gaps as a result of chronic conditions and their effects on the students overall academic achievement.

The early work of both Madan-Swain and Sexson offer additional support in my efforts of analyzing and understanding the cognitive implications of chronic conditions. In a Madan- Swain, Sexson (1992) study, they along with colleagues investigated cognitive and academic effects of intrathecal chemotherapy in school age patients. The results indicated that cognitive deficits in the area of visual-motor performance were tentative (Brown et al, 1992). Additionally, the offer-therapy group performed significantly more poorly than did the other groups on perception and organization of stimuli, short term-memory and focused attention, and complex motoric abilities; specifically eye-hand activities (Brown et al, 1992). Essentially, the results indicated that continual follow up is necessary as students undergoing treatment for chronic conditions demonstrate long and short term cognitive concerns. Understanding the ongoing implications of treatment and its side effects for a number of illnesses offers educators and leaders a significant opportunity to become more responsive in their approach to supporting students with chronic conditions who are both on

and off treatment. Limited knowledge about specific disease, and preconceived ideas about disorders developed through negative experiences may cause teachers and educational leaders to alter their interaction with students (Sexson & Madan-Swain, 1995; Sexson & Madan-Swain, 1993). This is especially important when students are long term survivors. The notion that lingering side effects is still possible as long as five or more years down the line is critical.

Given this, their collaborative research supports previous literature and serves as a foundation for continued research suggesting that school reentry for students must be an ongoing process between the home, medical team and school (Sexson, Mada- Swain, 1993). Leger (2014), in much more recent work, the researchers assert that the growing group of young students with chronic conditions are being identified as a hidden group of pupils, given that still today, the recognition of their needs is often missed. Participants, voiced that they recognized a the needs of students but in the case of Daniel the Disciplined, he did speak of being contacted by a middle school who received one of his previous students with significant medical needs as the staff did not fully understand the students' needs. This moment of reflection for Daniel the Disciplined forced him to evaluate the gaps in the academic and psychosocial transition of the student. Ultimately, he sent a staff member familiar with the student to the middle school campus to offer insight into managing the experience of the student.

This demonstrates the imperativeness of the study, barriers still serve as a burden in school settings for these students. It is difficult to fully discuss the implications of in-school models without first understanding that the transition back to school following any lengthy

absence due to illness is vital to the academic success of students with chronic condition.

Theis and Leger, have both contributed to the notion that though students with developmental disabilities are often appropriately served in school settings, those students who suffer from the challenge of a life limiting chronic condition are not supported sufficiently (Leger, 2011; Theis, 1999). Theis (1999) offers a significant reminder that these students suffer academically because of a poor fit between their needs and school environments. While, participants spoke generally well of their processes for managing the academic success of students with chronic conditions.

The discussion of mitigating any academic loss during transitions from homebound services back on campus was valuable to me as a researcher; as this transition is paramount. While, participants acknowledge that they understand the process of setting students up for homebound they did confirm that there was little to know communication or training between the homebound department and the school. The efforts of our participants engaging in timely communication with district homebound assigned teachers provide avenues for minimizing gaps that would impact student achievement. Utilizing technology to maintain communication with students on homebound were some strategies used and implemented in their schools by Daniel the Disciplined and Shane the Servant in their acts to impact academic achievement.

Each participant maintained that as a school leader, their expectations for academic achievement was not compromised due to any students' diagnosis of a chronic condition. They each communicated that their standards for academic success was not altered; however, how they facilitated the process by which students with chronic conditions

achieved success might look different.

**Research Question #4: How do administrators describe their leadership acts related to the social adjustment of chronically ill students?**

The trend of school administrators leading environments strictly focused on education is continuing to prove unreasonable. As diversity among the students continue to expand, so must the approach and practices of school leaders in ensuring that students are prepared to learn. In doing so, the school administrators in this study perceived that their role also extends into programming and managing personnel that will meet the psychosocial needs of students with chronic conditions. They often expressed that they are responsible for “IT ALL” and must provide any services to address ALL the needs of their students, specifically students with chronic conditions in the case of this study. The necessity in addressing psychosocial needs at the onset of diagnosis for young school age treatment is the implications for longterm side effects. Thies and McAllister (2001) asserts that in the case of cancer survivors students were less likely to graduate and more likely to require special education services as a result of long-term treatment. Addressing factors that contribute to these fatal outcomes should begin as quickly as possible.

Participants didn’t speak significantly to common psychosocial issues as addressed in the literature review such as absenteeism, depression, lack of energy and negative peer interactions, but they did acknowledge the implications of parental involvement, home life and economic influences often associated with urban communities and that commonly influence students’ ability to function within the school setting (Eiser & Vance, 2002; . Participants, highlighted some partnerships that school leaders have established or have

access to in an effort to impact the social adjustment of student with chronic conditions.

The study did however, correlate with previous data that recognized the value in taking a multi-disciplinary approach in meeting the needs of students returning to campus following extended hospital stays or homebound school placement. These transitions, as discussed in the literature are often meet with emerging psychosocial challenges. School leaders in this study validated the team approach but did not necessarily speak to the perceptions of their staff in serving these students as discussed in previous literature.

Kaffenberger (2006), discusses the role of the counselor in the to the school reentry process for students with chronic conditions. Understanding the role of each of your staff or school personnel is monumental for school leaders. According Newacheck & Halfon (1998), research illustrates that the most common childhood chronic conditions include asthma, allergic disorders, digestive disorders, central nervous system disorders, and seizure disorders (Shaw, 2006). As such, he in previous unpublished work, reported that school counselors engaged in a number of activities supporting students with chronic conditions such as facilitating 504 plans, collecting assignments and meeting with school leadership (Shaw, 2006). During this process, he reported that 71% of elementary school level counselors respectively felt unprepared to provide services. The ongoing need to prepare all professionals in the care of students with chronic conditions should continue to be a priority in the area of research and practice. It should also drive school administrators' attention toward managing the relationship between their counselors, who are often the catalyst for meeting the psychosocial needs of students in the school.

In a later study evaluating the perceptions of nurses, school personnel and parents

involved in the school reentry for children with cancer; school personnel reported that they performed some services to facilitate student's school reentry; however, they also communicated that additional education would be helpful (Moore, Kaffenberger, Goldberg, Mi Oh, & Hudspeth, 2009). The research supported findings from previous literature that suggested there is a provision of inconsistent services and support for school reentry and poor communication between health care and school service providers (Moore et al, 2009). This inconsistency likely contributes to the seemingly minimal but important attention toward meeting the psychosocial needs of students with chronic conditions.

### **The Missing Link and New Findings**

As I evaluated the data from this study, there was a missing link that arose.

Essentially the data revealed that participants were keenly unaware of the significance of a comprehensive school re-entry or transition model for students' imperative to the ongoing management of students with chronic conditions. Though the participants spoke about conducting aspects of what previous research has deemed important in any school re-entry model, they spoke without regard for following a comprehensive plan. The research revealed a haphazard implementation of services for managing students with chronic conditions. It is evident that despite research this organized process is missing from the House of Healing systems.

Sexson and Madan-Swain (1993) describes four successful guidelines that have proven useful in the facilitating school re-entry or transition for students with chronic conditions: a.) preparation of the child and family, b.) preparation of the school personnel, c.) preparation of the class and d.) continued follow-up after the child returns to school. In

more recent published research, Canter and Roberts (2009), reported school personnel workshops, peer education programs, or comprehensive programs. These systems are necessary in bridging the gap between the patient, family, school and the healthcare system.

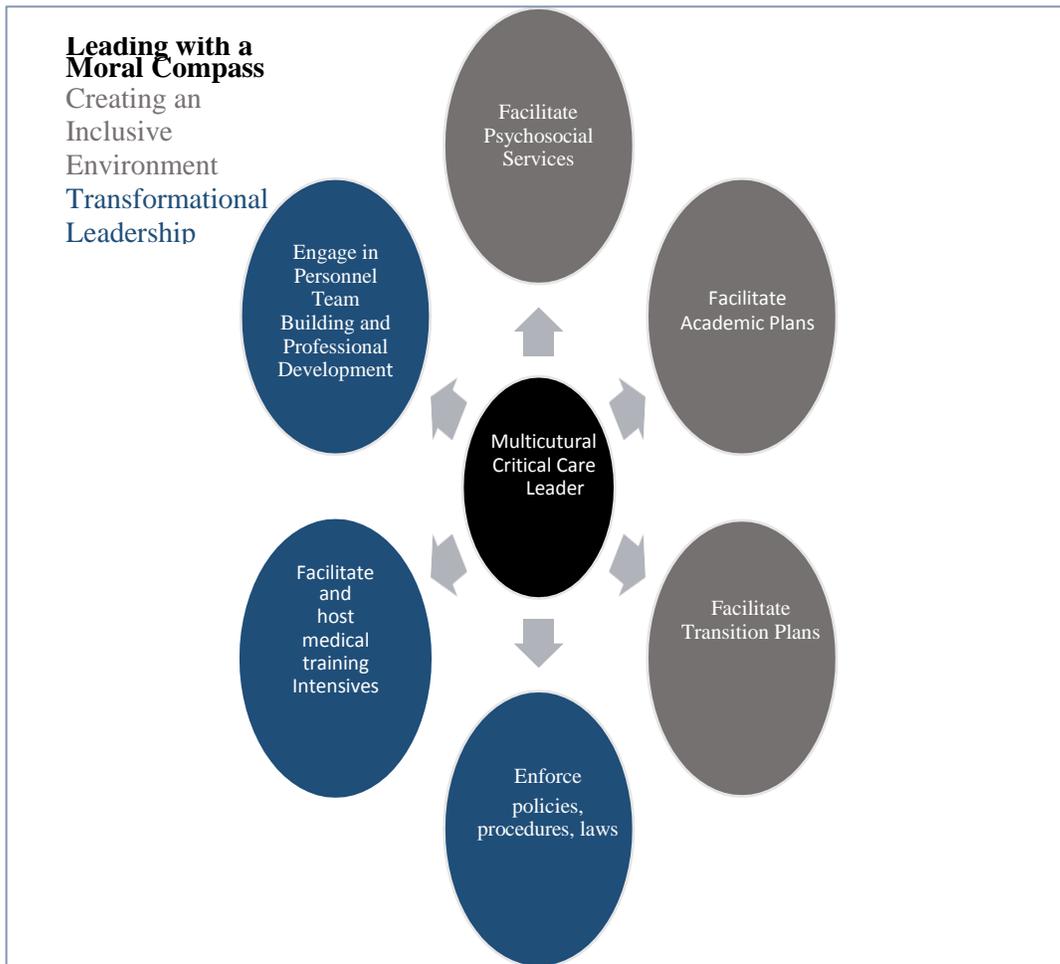
Neither of the participants during the study, communicated information regarding a designed school model. This validates the need for continued research in the management of students with chronic conditions and the need for more communications between schools and healthcare systems. When asked about a school- reentry model, Daniel the Disciplined, began writing a note on a post note and acknowledged that this was indeed worth considering.

### **Critical Care Leader**

At the core of this research was a Multicultural Ethics of Care Framework to manage ethnically diverse students with chronic conditions in urban schools. The integration of care in the management of students with chronic conditions was prevalent through much of the study, as school leaders confirmed critical areas of focus in the management of students with chronic conditions. As I journeyed through the house of healing after sharing the stories of each participant, I conceptualized the school leader as a Multicultural Critical Care facilitator whose moral compass guides their every approach to managing the care of students in their schools who sit at the intersection of health and educational needs. Essentially, the multicultural critical care leader understands the diverse needs that are often associated with urban communities, thus at the core of being the primary facilitator of services in the school, knowledge of the environment is paramount in this critical care approach. Their commitment to care is reflected in each of the areas

emphasized in the W.C. Hayes Multicultural Critical Care Leadership model below:

**Figure 3: W.C. Hayes Multicultural Critical Care Leadership Model**



At the center or core of this model is a multicultural critical care leader who believes that caring and social justice is the foundation for facilitating their leadership practices in the management of students with chronic conditions (Pang, 2005). Valerie O' Pang (2005) affirms that caring is at the center of a democratic society and as such this foundation is

imperative for school leaders and educators with a deep affinity for equality and equitable school services for all students.

In this case, I am reminded of Daniel the Disciplined who communicates "...you have to care, number one...when I say care I'm not talking about some this triteness that people... (you have to know) that I really care about kids".

This model also illuminates that the principal of multiculturalism is predicated upon a familial environment and a leader that cares for others, themselves and the community in which they serve. Eve the Exuberant confirms, "I like being connected to the community". This study revealed that the multicultural critical care leader also recognizes the importance of community and family as a critical aspect of serving, leading and operating within the schools and in the management of students with chronic conditions. Further, the leader, comprehends the impact of culture and the influence that life experiences has on the way students interact and respond within the school environment. This is particularly important because these same experiences and cultural implications play a significant role in the way students and their families will manage chronic health conditions; both in isolation of and in conjunction with their school experience. The individual that sits at the core of this model, is fully capable of examining the all these separate influences and is dedicated to maximizing this knowledge to ensure a successful school experience.

The model highlights six critical areas that extend from the multicultural critical care leader, all of which indicate the leader's primary functions in managing the care of students within the schools, affectionately referred to in this study as the House of Healing. The design is developed to communicate that at any given moment the critical care leader should

be prepared to facilitate any one of the critical functions in the process of managing students with chronic conditions. Since participants in this study validated previous research in that few processes were officially documented in terms of managing students with chronic conditions, formally identifying these critical areas were necessary (Moore, et.al, 2009).

Facilitating academic, psychosocial and transitions (school-re-entry) plans are key components of the model, because they support the overall academic achievement and social adjustment success of students. These processes represent the creating an inclusive culture in the House of Healing. The academic component focuses on ensuring that students have access to all content related material and lessons despite diagnosis. In this model, the critical care multicultural leader should establish systems to ascertain that academic plans for all students with chronic conditions are effective, consistently monitored and relevant to the success of students. On the other end of the spectrum, psychosocial plans should support continued access to appropriate psychological, psychiatric, counseling, social work, parental support and other support services to ensure the mental well-being of all students with chronic conditions. Facilitating transition plans or school reentry plans as referred to in other research acknowledges the leaders ability to ensure that all plans are in place to maintain open communication with the student and family regardless of the stage of diagnosis or treatment. This comprehensive transition plan is led by the facilitator to communicate that regardless of where the student is medically, a system to support their continued connection to the House of Healing is important and certain.

In the area of transformational leadership, the morally driven caring centered multicultural leader should focus on three primary functions in the process of managing

students with chronic health conditions. The leader is the primary facilitator in engaging the appropriate teams of personnel, while strategically ensuring appropriate professional development is conducted and is available. The study revealed a lack of professional development offerings at the district level, therefore, leaders at the district and school level can serve interchangeably in the critical care leadership role to ensure that these functions are being facilitated. Another function in the model is to bridge the gap between medical and educational professionals but hosting medical intensives to cross train professionals involved in the care of students with medical conditions. In this case, research suggest a lack of confidence among educators in the area of knowledge and being comfortable with serving students with chronic health conditions. A multicultural critical care leader will help build the gaps. The final function is to enforce and monitor the implantation of local, state and national policies. In caring for students with chronic conditions, an efficient leader will do everything possible within legal parameters to ensure that students are managed and cared for at exceptional levels. To ascertain that this takes place, the leader in this model is proactive and reliable in this function.

### **Recommendations**

Based on the voices, experiences, perceptions and practices of the participants in the study, a critical care approach as illustrated in Figure 3 for school and district level leaders is recommended to impact the management of students with chronic health conditions. The following recommendations are based upon my interactions with participants, my engagement in previous literature and personal experience as a school liaison:

- 1.) School Administrators need an extensive understanding of the capacity of their

role and the span of their impact; therefore district level 3 year leadership preparation programs are recommended. Thus, leadership intensives with emphasis on managing rare but prevalent subpopulations of students with diverse needs is necessary. The participants in the study all placed a significant amount of focus on expanded impact of their action. This intensive should cover development areas such as identifying subpopulations of students with unique needs, critical management strategies for developing sound plans for serving these populations, effective communication strategies, and confidentiality. For example, integrating a 3 year mentorship leadership program for all school administrators designed to develop their leadership capacity would ascertain that they received essential guidance and support during their critical development years as an administrator.

2.) With school districts growing increasingly more diverse with students racially, culturally, physically and emotionally, it is recommended that school leaders undergo multi-cultural ethics of care diversity training programs to get insight on the changing dynamics of their students, their families and the realities of their communities. Participants discussed the importance of exhibiting compassion, care and understanding throughout the study. As such targeted sessions to promote leading with a moral compass among diverse populations is imperative. Further, as defined by Valle (1997), examining the customs, practices and interactional patterns of multicultural students living with chronic health conditions. Understanding these patterns and interactions

provides school leaders with the leverage necessary to understand not just the students culturally but how their cultural or racial background now influences their ability to manage chronic conditions. These trainings are paramount in developing intercultural sensitivity when students or their care takers react differently to medical and academic directives than what is expected of them.

3.) It is recommended that school leaders engage in a multi-disciplinary medical intensive training program in coordination with the district homebound department and the district nursing leader to provide training regarding common chronic health conditions among school age youth, implications of treatment and potential short and long term effect of treatment. The literature review offered examples of common childhood chronic conditions, which should be crossed referenced with a list of conditions identified in the district to help drive the medical intensive training programs. For example, an intensive covering long-term cognitive implications for students 3-8 years off treatment for cancer would be beneficial for administrators and engaged personnel members. Another example of an intensive would be conducting an organized published journal read on managing the care of students with Type I diabetes. These journal reads should include multidisciplinary team members with a culminating chew and chat session that allows each team member to identify, define and develop talking points for improving their practices with students attending school with Type I diabetes. Engaging in

these journal reads will expose all personnel to the latest in treatment, documented medical trends and responses among childhood patients allowing for them to critical apply this information to their practices within the school.

- 4.) Districts should integrate school-reentry or transition plans in all critical care models for supporting students with chronic health conditions. Participants revealed that there is some level of inadequacies in how they service students with chronic conditions, given the fact that no district model is currently developed. District level and school leaders should establish standard of care plans with uniformed activities, services and processes for all identified students with chronic conditions. Though participants revealed that currently provide services to meet the needs of the patients, district wide models should be established with a space for customization to meet the unique medical needs of each student.
- 5.) To address the needs of chronically ill students within the district, leadership should also evaluate integrating the use of medical school liaisons. Data from this study revealed that school leaders rely on partnerships with district CYS workers to help support families with extraordinary needs. A designated medical school liaison would work toward streamlining communication between students medical teams, seeking additional support to help minimize family burdens, communicate with district homebound personnel, advocating for students on campus and providing school level training to support school

administrators in the management of students with chronic conditions.

6.) Given that this study revealed little support was being provided in the form of training for school leaders and district staff in general, it is recommended that a more rigorous analysis of the Texas Education Codes that addresses or has to address in greater detail students with chronic conditions is completed. For example, Texas Code Chapter 89 Sub Chapter D Special Education Services and Settings detail that students requiring homebound are expected to be confined for a minimum of 4 consecutive weeks as documented by a licensed physician for homebound or hospital school services. Given the advancements of medical treatments, students with chronic conditions may not require 4 weeks of services but access to certified educators is paramount to their academic and social progress. Further state requirements caps services to a maximum of 4 hours of instruction a week. In preparation for successful transitions back onto campus, the Texas Education Agency should also evaluate this imposed practices as students who are medically able should have access to more than 4 hours of instruction. Ultimately this study should be used in conjunction with others as a tool to evaluate the current codes by leveraging the voices within this study to fill gaps in the governing systems.

### **Implications for Future Studies**

Based on the findings of this study the following are suggestions for further research:

1.) This study focused on elementary administrators, however an increasing

amount of research focuses on the long-term cognitive effects of students receiving early treatment. As a result, it would be interesting to replicate this study at the middle school and high school level.

- 2.) Little research exist on the effectiveness of district homebound programs servicing students with chronic conditions who are unable to attend school in the general setting. A future study that examines the voices of district homebound directors and their role academic success of students with chronic conditions offers an opportunity for further research.
- 3.) Policy, Processes and Planning: The Superintendents Perceptions of Onsite School Health Centers serving students within Urban School Districts. With the increasing presence of on-site school health centers, this proposed study sets the stage for district leadership to critically examine the intersection between health care and education and the impact the intersection has on urban communities.
- 4.) An Examination of School Nurses Perceptions of Support Services for Medically Fragile Students in Urban Middle Schools is a study that lends itself to directly impacting school level programming for students with chronic conditions and the role school nurses play in this precarious process.
- 5.) The Voice of the District's Head Nurse: Examining the Care and Academic Achievement of Students with Chronic Health Conditions in an Urban School District, is a future study with the potential to provide a critical analysis of nursing leadership at the district level, and their perceived roles in

managing the care of students with chronic conditions.

### **Conclusion**

“Paging all school leaders...Paging all school leaders” please report to your House of Healing. Just as the ER doctor is paged and expeditiously summoned to the triage or emergency unit to address the critical care needs of patients with emergent medical needs, this study unequivocally offers an extraordinary parallel for students with chronic health conditions in the school environment. This study reveals that school and district leadership should be summoned to the critical care units (training centers) of their schools to address emergent psychosocial and academic needs of student with chronic conditions within the school environment.

A liken to the desperation of an asthmatic student in need of oxygen. Albeit scary and a bit extreme, medical doctors are expected to be prepared to administer the right medications necessary to stabilize the young patients breathing. It requires a mental poise and promptness to address what we can all imagine to be a frantic and overwhelmed patient. They are expected to outline all necessary medical road maps to support in the moment care of the patient; while communicating to all other involved medical professionals engaged in the urgent process. Further, once stabilized the medical doctor is required to communicate long term treatment maps for all medical and support staff who is involved in the critical follow up care of the patient. They are expected to write the appropriate orders for long and short term medicines and are relied upon to deliver all pertinent information critical to the care of the patient to any given person at any given time. Throughout the entire process, clear, precise and reliable information is expected to be provided to the parents and or

caretakers throughout every phase of this experience. There is an unwavering notion that hospitals are operated as a well-oiled machine and while loop holes may be encountered, there is an undeniable expectation that things are in order to meet the needs of patients. These are the expectations carried for medical professionals within medical institutions across the country

### ***The House of Healing***

The House of Healing (schools) should carry this same expectation. Education is the very oxygen our students, regardless of their medical condition require in order to develop into self-sufficient citizens within our communities. As charge professionals of Houses of Healing, school administrators, much like medical doctors, are expected to identify the critical needs of the students when they are released to return to school following visits to medical institutions. School leaders are expected to follow appropriate policies and guidelines to implement emergent and sometimes urgent plans to address a range of medical and academic needs that may arise. They are expected to lead in the development of critical care plans; while soliciting all necessary personnel who need to be involved in the process. They like medical professionals must develop an in house rhythm that allows for seamless operations in the care of students with chronic conditions. It's just as critical as care within hospitals and requires an infallible approach to serving students with various medical diagnosis', treatment needs, and academic backgrounds. This is the expectation for what should be efficient Houses of Healing for ALL students, especially those with medical conditions.

The parallels between medical institutions are evident; yet, this study reveals that

much work is needed to improve the systems we refer to Houses of Healing. A House of Healing, primarily functions as an environment in which the process of learning occurs. What this study acknowledges is that the process of learning is often significantly impacted by various factors, such as, cancer, asthma, diabetes, and other life altering chronic health conditions. This research affirms that these systems need improvement as it relates to simultaneously addressing the academic and psychosocial needs of students with chronic health conditions. As a result of advance medical care, a growing number of school age students return to the Houses of Healing and are being served through the educational system in some capacity. As such we cannot miss this opportunity to analyze the voices of our charge leaders, our school administrators, the individuals paged to the emergent care units of our Houses of Healing. Moreover, the research substantiates ongoing evaluation of health services available within these Houses of Healing. Though empirical data is generally minimal, this study is among an increasing number of published reports making a concerted effort to contribute to the growing body of research. The intent of this study was to create a connection between the limited research available and the extraordinary opportunity to expand upon published content.

As with any study, the implications for future studies lends itself to contributing to a growing body of work regarding the management for students with chronic conditions in the school environment. Future research should continue the necessary discourse surrounding the intersection between health and educational institutions and access to quality educational opportunities for every student in the school system despite the presence of medical disease. Further, this study showed that the role of school administrators' endeavors

to evolve and their direct engagement beyond administrative responsibilities is critical in the care of extraordinarily vulnerable populations such as those with chronic conditions.

Lastly, although administrators are operating with the greatest of intentions across this country, schools are still faced with increasing opportunities to ascertain that ALL students receive equitable and ethical services, even those not often discussed. My hope is that the stories of these bold administrators who answered our page and shared their experiences working directly with students with chronic conditions will resonate with policy makers, district leaders, other school leaders and educators across the country.

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## APPENDIX A

### Literature Conceptual Framework



## **APPENDIX B**

### **Consent Form**

Investigator: Wykesha Hayes  
Home: (281)235-3928  
Work: (281)235-3928

**Project Title:** Meeting The Needs of Medically Fragile/Chronically Ill Students: Through the Lens of the Urban School Administrator

**You are being invited to take part in a research study being conducted by Texas A&M University. You are being asked to read this form so that ensure that you have a strong understanding of this research study. The information in this form is provided to help you decide whether or not to take part in this research. If you decide to take part in the study, you will be asked to sign this consent form. If you decide you do not want to participate, there will be no penalty to you, and you will not lose any benefit you normally would have.**

#### **Why Is This Study Being Done?**

The purpose of this study is to examine and interpret the experiences, knowledge and management practices of Urban school administrators-how they describe their personal characteristics related to managing students with chronic conditions, how they exercise and interpret their acts in the educational management of chronically ill students, and how do they describe their leadership acts that influence or impact the academic achievement and social adjustment of students with chronic conditions.

#### **Why Am I Being Asked To Be In This Study?**

You are being asked to be in this study because you are an Urban School Administrator having served in your position for a minimum of 3 years, and you are currently have at least one student on your campus having been identified as a student with a chronic condition.

#### **How Many People Will Be Asked To Be In This Study?**

Three-Five people will be enrolled in this study locally.

#### **What Are The Alternative To Being In This Study?**

The alternative is not to participate.

#### **What Will I Be Asked To Do In This Study?**

Your participation in this study will last up to two hours. The procedures you will be asked to perform are described below:

The visit will last about 60 to 90 minutes. During this visit or interview, I will ask questions from an interview protocol/questionnaire. In order to get the exact information from you, and increase the strength of the study, you will be audio taped in the 60 to 90 minute interview session.

Your name will be pre-coded to the recording tape that will be used to record the interview session. The transcriptions (writing down from the tape what you said) will also be coded in order to further protect your confidentiality. Written reports may entail the use of quoted material. At the conclusion of this study, the information gathered and audio tapes, identifiable only by subject number will be stored in a locked file that only I will be able to access.

Follow Up visits may occur which will last up to 30 minutes.

A visit will include but may not be limited to face to face visit, phone chat, or face to face web chat via online web chat services (i.e. Skype or Gmail).

### **Will Video or Audio Recordings Be Made Of Me During the Study?**

#### ***Required recordings:***

The researchers will take an audio recording during the study so that exact information from me, the participant is collected and to increase the strength of the study. If you do not give permission for the audio recording to be obtained, you cannot participate in this study.

\_\_\_\_\_ I give permission for audio recordings to be made of me during my participation in this research study.

\_\_\_\_\_ I do not give my permission for audio recordings to be made of me during my participation in this research study.

### **Are There Any Risks To Me:**

There will be no more risks than you would come across in your everyday life.

### **Are There Any Benefits To Me?**

There is no direct benefit to you by being in this study. What researchers find out from this study will help provide insight about Urban school administrators and how they manage the intersection between education and health care in the school setting; specifically how they view their knowledge, practices, roles, influence and impact in the academic and social development/performance of students with chronic conditions.

Additionally, administrators as well as universities and colleges can use this study to create preparation programs for educators and administrators in the effective management of students with chronic conditions.

**Will There Be Any Costs To Me?**

There will be no costs for taking part in this study, aside from your time.

**Will I Be Paid To Be In This Study?**

You will not be paid for being in this study.

**Will Information From This Study be Kept Private?**

The records in this study will be kept private. No identifiers linking you to this study will be included in any sort of report that might be published. Research records will be stored securely and only Wykesha C. Hayes will have access to the records.

Information about you will be stored in a locked file cabinet. This consent form will be filed securely in an official area.

Information about you will be kept confidential to the extent permitted or required by law. People who have access to your information include the Principal Investigator and research personnel. Representatives of regulatory agencies such as the Office of Human Research Protections (OHRP) and entities such as the Texas A&M University Human Subjects Protection Program may access your records to make sure the study is being run correctly and that information is collected properly.

**Who May I Contact for More Information?**

You may contact the Principal Investigator, Wykesha C. Hayes, M.Ed to tell him/her about a concern or complaint about this research at 281-235-3928 or [wchayes@tamu.edu](mailto:wchayes@tamu.edu). You may also contact Dr. Norvella Carter, at Texas A&M University at (979-862-3802) or [ncarter@tamu.edu](mailto:ncarter@tamu.edu) or Idethia Harvey (979-862-2954) or [idethia.harvey@hlkn.tamu.edu](mailto:idethia.harvey@hlkn.tamu.edu), the faculty advisors for this project. This research has been reviewed by Institutional Review Board at Texas A&M University.

For questions about your rights as a research participant; or if you have questions, complaints, or concerns about the research, you may call the Texas A&M University Human Subjects Protection Program office at (979)458-4067 or [irb@tamu.edu](mailto:irb@tamu.edu).

**STATEMENT OF CONSENT**

**I agree to be in this study and know that I am not giving up any legal rights by signing this form. The procedures, risks and benefits have been explained to me, and my questions have been answered. I know that new information about this research study will be provided to me as it becomes available and that the researcher will tell me if I must be removed from the study. I can ask more questions if I would like and a copy of this entire consent form will be given to me.**

---

Participant's Signature

Date

---

Printed Name

Date

**INVESTIGATOR'S AFFIDAVIT:**

Either I have or my agent has carefully explained to the participant the nature of the above project. I hereby certify that to the best of my knowledge the person who signed this consent form was informed of the nature, demands, benefits, and risks involved in his/her participation.

---

Signature of Presenter

Date

---

Printed Name

Date

## APPENDIX C

**Title:** *Meeting The Needs of Medically Fragile/Chronically Ill Students: Through the Lens of the Urban School Administrator*

This is an interview with \_\_\_\_\_ conducted by Wykesha Hayes, PhD candidate at Texas A&M University, Teaching Learning and Culture- Urban Education.

Today is \_\_\_\_\_. The time is: \_\_\_\_\_

This interview is being conducted as part of a research study “Meeting the Needs of Medically Fragile/Chronically Ill Students: Through the Lens of the Urban School Administrator.”

This is meeting **1** of this interview.

The purpose of this study is to examine and interpret the experiences, knowledge and management practices of urban school administrators-how they describe their personal characteristics related to managing students with chronic conditions, how they exercise and interpret their acts in the educational management of chronically ill students, and how do they describe their leadership acts that influence or impact the academic achievement and social adjustment of students with chronic conditions.

To begin this interview, I would like to start with some information related to you, your background and your career.

### **Background and Career Information**

- 1.) Tell me something about yourself
- 2.) Please provide your formal educational background?
- 3.) How many years of elementary teaching experiencing did you have prior to becoming a school leader? In an urban setting?
- 4.) How many years have you been employed as an administrator in this district (others)?

5.) Talk about your transition to being an administrator in an urban setting?

6.) Prior to being an administrator did you have any experience working with medically fragile student(s)?

7.) Describe what you would consider to be the most appealing aspect of being a school administrator? (managing students with chronic conditions)

8.) Is there anything you consider to be the least appealing aspect of being an administrator in an setting? (managing students with chronic conditions)

### **Qualities/Effectiveness**

1.) What do you feel are some of the significant personal qualities, values and behaviors necessary for administrators involved in managing the school experience of medically fragile students or those with chronic conditions?

2.) What do you think are some of your strong qualities as an urban administrator that has helped you in your leadership role, particularly managing the needs of students with chronic conditions?

3.) Please share some of the important life experiences that you have had which may impact your ability to manage the school experiences of medically fragile students?

4.) What interpersonal dynamics do you feel has impacted your effectiveness as a leader managing the urban school experiences of students with chronic conditions?

5.) What role, if any, did your upbringing play in the way you lead in your school environments? (manage students with chronic conditions)

6.) What values, interests, goals and beliefs influence the way you conduct yourself personally and professionally when addressing the needs of students with extraordinary medically needs?

7.) As an administrator does perception of a student's chronic condition influence access to services or the management of his/her's educational/behavioral plan?

8.) Please describe some of the obstacles or restrictions that cause you the most concern as you try to carry out your duties as a school leader in a school setting?

9.) Specifically obstacles directly associated with managing students with medical conditions in the school environment?

10.) What role should the school administrator play in managing the school experience of students with chronic medical conditions in the school environment?

11.) How should the role be redefined as it stands now and distributed among other school administrators, teachers and other school personnel?

### **Impact of Effective Leadership**

1.) As a school leader, how did you go about establishing a school management plan for meeting the academic needs and social needs of your students?

2.) How do you go about establishing a successful learning environment for students with chronic conditions?

3.) Please describe some of the approaches/techniques/systems you used in successfully managing students with chronic conditions within your school and district?

4.) Please name key characteristics that enable leaders to guide successful change in addressing the needs of students with chronic conditions.

5.) What process or system have you implemented within your school to support students with chronic conditions?

6.) What committee do you have in place to support the school experience of students with chronic conditions and what are the roles of those committee members?

7.) Have you developed a list of community partners to help support students with significant needs? If so how did you go about building a circle of partners?

8.) Explain how developing a circle of partners is both a benefit and a detriment to your success and effectiveness in managing the school experience of students with chronic conditions

9.) Do you have a school re-entry model in place for medically fragile students returning to campus following an extended medically required absence (ie. homebound/hospital)? What does this look like?

10.) If administrators play an important part in the success of their schools/districts response to managing students with chronic health condition, what are their secrets and what are the limits to their powers?

### **Training and Development of Administrators Serving Medically Fragile Students**

- 1.) What training have you received as a school administrator relevant to managing students with chronic conditions?
- 2.) What trainings have you coordinated or had coordinated to support school staff in managing students with chronic conditions?
- 3.) What chronic conditions have directly impacted students within your school? What chronic conditions do you perceive to most commonly impact students in urban environments?
- 4.) In the event students require school services outside the school environment (ie.Homebound or hospital) what is your role as an administrator?
- 5.) What is your current knowledge of homebound services/policies provided to students in your school district? (How does this impact your role or practices when they reintegrate back onto campus?)
- 6.) What are the needs of students with chronic conditions? What role should the administrator play in meeting the needs of these students?
- 7.) What policies or laws are most relevant in managing students with chronic conditions? (At the local, state and federal level).

### **Managing in Urban Environments**

- 1.) What racial ethnic or social economic concerns do you have as it relates to your role in managing the school experience of medically fragile students in urban environments?
- 2.) What factors in the urban environment if any do you perceive as obstacles to managing the school experience of medically fragile students?
- 3.) What is your greatest academic/behavioral/social management concern as you reflect on your professional responsibilities and the medically fragile students you serve?

### **Summarization Question:**

Is there anything I did not ask or that you have not mentioned that you would like to add about yourself, about your experience, about serving medically fragile students within the school environment, and/or about the development of administrators in urban schools equipped to manage students with chronic conditions?

We have come to the conclusion of our interview. I thank you for your

participation in this study.

## **APPENDIX D**

### **Recruitment Email Script**

Hello, I am Wykesha C. Hayes, a doctoral student at Texas A&M University and I am conducting a study on administrators and their involvement in the management of medically fragile students in urban environments. In order to gain more insight and information on this topic, I would like to interview five elementary school administrators. The risks associated in this study are minimal, and are not greater than risks ordinarily encountered in daily life. There will be no costs for taking part in this study, aside from your time. Your participation in this study will last about 60 to 90 minutes. A follow up visit may occur which will last up to 30 minutes. All information gathered during the study will be confidential. Please respond to this email stating your interest at [wchayes@tamu.edu](mailto:wchayes@tamu.edu) or contact me at 281-235-3928 in order to further discuss your participation in this study.

Yours truly,

Wykesha C. Hayes, M.Ed. PhD Candidate

Texas A&M University

## **APPENDIX E**

### **Phone Script**

Hello, I am Wykesha C. Hayes, a doctoral student at Texas A&M University and I am conducting a study on administrators and their involvement in the management of medically fragile students in urban environments. In order to get more information on this topic, I would like to interview three to five administrators. The interview will last approximately 60 to 90 minutes and will be at a location of your choice. A follow up visit may occur which will last up to 30 minutes. The risks associated in this study are minimal, and are not greater than risks ordinarily encountered in daily life.

All information gathered during the study will be confidential. I will be the only person with access to your consent form, which links your name with the subject number. Your identity will be disguised through this specific coding. In order to get exact information from you, and increase the strength of the study, you will be audio taped in the 60 to 90 minute interview session.

Your name will be pre-coded to the recording tape that will be used to record the interview session. The transcriptions (writing down from the tape what you said) will also be coded in order to further protect you confidentiality. Written reports may entail the use of quoted material. At the conclusion of the study, the information gathered and audiotapes, identifiable only by subject number, will be stored in a locked file that only I will be able to access. The information obtained from this research will be used for the publication or educational purposes of this researcher only and nor for any other purpose.