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**HOSPITAL-BASED EDUCATIONAL SERVICES AND THE WELL-BEING  
OF CHILDREN WITH CHRONIC ILLNESS: A SELF-STUDY**

Presented to the Faculty of the Graduate Division of the School of Education  
In Partial Completion of the Requirements for a Master of Arts Degree

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Chicago, IL

## Abstract

### A Self-Study of the Relationship Between Education and Chronic Illness

Samantha Gold Oberstein

While medical progress has incited great change in the epidemiology of child health in the United States, chronic illness now accounts for the majority of pediatric hospitalizations, posing a major challenge to educators in regards to the availability and provision of academic services. The purpose of this qualitative self-study is to better understand the effects of educational services on the development of children with chronic illness during long-term hospitalizations. Research consists of an examination of and reflection on the intersection of Education and Healthcare in the pediatric hospital environment and the population of students caught in its crossfire. Future implications suggest a need for the development and implementation of pediatric hospital-based school service programs throughout the United States, as well as a reconsideration of our prioritization of care. An attempt was made to identify resources to highlight and develop recommendations for improvement in communication, outreach, and advocacy efforts.

*Keywords: Chronic Illness, Pediatric Health, Hospital School, Special Education, Early Childhood Education*

### *Acknowledgements*

While I consider reading Anne Fadiman's *The Spirit Catches You and You Fall Down* to be a pivotal point in my graduate school career, it was Professor Donna Smith who first introduced me to the narrative nonfiction and who led me to seek out an internship in a pediatric hospital, ultimately laying ground for the foundation of this study. Donna recognized in me an appetite for something greater from my Early Childhood program, and her own passion for education and thirst for knowledge only reinforced the possibilities. I feel incredibly fortunate not only to have her as my mentor, but also to call her my friend.

Per Donna's suggestion, I began reaching out to area hospitals for information about potential internships. After several unreturned voicemails, it was something greater than luck that connected me to Pat Ebervein, superwoman and director of School Services at Children's Memorial, now Lurie Children's Hospital, in Chicago. Without question or hesitation (and certainly without obligation), Pat invited me into her world, and she changed my life. Over the past few years I've watched her tirelessly advocate for her students, alone often taking on the work of an entire department, and almost always with an infectious smile on her face. I admire her, I am in awe of her, and I cannot thank her enough.

When it came time to turn this incredible newfound opportunity into an academic reality, in stepped Dr. Mojdeh Bayat, whose wisdom and knowledge has guided me through each step of this seemingly never-ending process. Mojdeh truly embodies the model of 'care' I seek to provide my students. Her compassion and dedication to her own work is remarkable and the amount of respect I have for her, boundless.

And lastly I want to thank my mom, for instilling in me a passion to wrestle for what is right and the conviction that it is my duty as a human being to speak up for those who cannot or do not know how to speak for themselves. I know that my aspiration for equity in education is deeply rooted in her inspiring perpetual struggle for social justice. I also know that I am an advocate for these kids because she is one for me.

To these four women, I am endlessly indebted. If only every child could have such teachers.

## Chapter I. INTRODUCTION

### *Significance and Background*

Unbeknownst to me at the time, the impetus behind this project originated as required reading for my very first Graduate School course, *Children and Family in the Multicultural Community*. The course was designed to examine the role of culture influenced by a variety of contexts, as they related to child development. However, unintentionally and ultimately invaluable, it provided me with a glimpse into an alternate professional niche of non-traditional Education.

Our final assignment for the quarter was to produce an analysis of and reflection on *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, written by Anne Fadiman. Prior to reading this tangled and touching novel, I had little exposure to hospital environments or to medical culture. Nor would I have imagined that the capstone experience of my graduate program would exist in the form of an internship, with the school services department of a children's hospital.

Fadiman's book serves as a study of cross-cultural medicine and a lesson in communication. It portrays the reprehensible discord between two incongruent cultures and its effects on the treatment of a child with a severe chronic illness.

In *Spirit*, readers are led to believe that Lia Lee's life is ruined by a series of cultural misunderstandings; a clash of traditional American medicinal practices and even more traditional Hmong spiritual beliefs. Fadiman (1997) implies that "conjoint treatment," one that takes into consideration "a concern for the psychosocial and cultural facets that give illness context and meaning," (p. 265) often improves the

outcome of undesirable prognoses, because chronic illness is so deeply affected by psychosocial-emotional factors.

My experience as an intern in a hospital school has provided me with similar exposure to multifaceted treatments of chronic childhood illness and to a somewhat forced weaving of two divergent systems. As healthcare and education collide in the pediatric hospital environment, school services aim to function as part of the “healing art” practiced alongside Western medicine. Meanwhile, its population forces us to re-evaluate our concept of progress, with regards to ‘special education’, in the American Education and Health Care systems.

Throughout this study, I was fortunate enough to work closely alongside the coordinator of Educational Services at one of the most prestigious pediatric hospitals in the country. This unparalleled experience, in a terribly challenging yet incredibly rewarding educational environment, has allowed me to meaningfully explore the relationship between theory, practice and inquiry in the form of a self-study. The backbone of this study is based on the reflections of my observations during my time as an intern in the school services department at a children’s hospital, in a large metropolitan mid-western city.

### ***Purpose and Rationale***

The purpose of this qualitative self-study is to broaden the existing knowledge of the effects of educational services on the development of children with chronic illness during periods of long-term hospitalization. It will allow for a greater understanding of how medical and educational organizations might collaborate to

meet the current challenges involved in supporting this aspect of development, in the face of incongruently rapid changes in the improvement of health care and practice. The focus of this paper is not on illness, but on the positive impact of educational services for children with chronic illness; detailing the availability, provision and success of a pediatric hospital-based school service program.

In addition to an examination of the academic needs of this population, this study will attempt to analyze the available educational programming consistent with both the United States Department of Education and the United States Health Care systems. Lastly, it will seek to identify resources to ameliorate some of the negative effects of chronic illness and hospitalization on the significant and normalizing experience of a childhood education.

### ***Identification and Definitions of Key Concepts***

While defining a Hospital School is in small part a facet of this study, generally speaking, these institutions consist of educational programs provided to school-aged patients within a hospital environment. Upon further examination, Breitweiser and Lubker (1991) suggest that hospital schools are unique, “in that they often have membership in two of the most powerful service systems in our society: the health care system and the education system” (p. 27). The authors go on to explain that “hospital schools provide academic programs for children both to promote normalizing activities in an abnormal environment and to minimize interruption of studies when children are hospitalized” (Breitweiser and Lubker, 1991, p. 31). For the purposes of this study, a hospital school refers to academic

services provided by the School Services department, a division of Family Services, to school-aged patients in a pediatric hospital. The services consist of academic instruction provided either in the hospital's classroom or at a child's bedside, by a certified teacher or trained volunteer. Children who participate in this program are either out of city district or are private, parochial, or preschool students, therefore are not eligible for local public school services. They are generally considered to be chronically ill.

According to Brown and DuPaul (1999), chronic illnesses include “those diseases involving a protracted course that may be fatal or result in compromised mental, cognitive and/or physical functioning and that are often characterized by acute complications, which may result in hospitalizations or other forms of intensive treatment” (p. 175). A second guiding definition, provided by Thies (1999) explains that:

Health professionals typically use the term “chronic health condition” when referring to two of the three overlapping groups of “children with special needs.” Those two groups include the broad array of developmental disabilities and chronic medical illnesses whose cause, symptoms, and treatment reflect pathophysiology of major body systems. Thus the terms “chronic health condition” and “special health care needs,” and the populations they represent, are similar but not synonymous. The latter refers to a population entitled to certain services; the former does not. (p. 393)

Although a more in-depth discussion of federal laws and acts governing the educational provisions for students with chronic illness will be included in chapters



two and four, it would be beneficial to identify a few key concepts at this time, beginning with a more definitive definition of Special Education. Excerpted from the Individuals with Disabilities Education Act (IDEA) the term ‘special education’ is defined as “specifically designed instruction at no cost to parents or guardians, to meet the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions.” 20 U.S.C. § 1401(29) (1997).

Most children eligible for school services during periods of hospitalization fall under the category of ‘Other Health Impaired’. Other Health Impairment refers to those students with “limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (i) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and (ii) adversely affects a child's educational performance,” (Assistance to States For the Education of Children with Disabilities, 2006). In order for a child to be considered OHI (Other Health Impaired) he or she must meet several distinctions. Not only must the child suffer from an acute or chronic illness, but that health condition must cause limited alertness or responsiveness to the educational environment and must also affect the child’s educational performance. Lastly, the condition must create a need for special education services.

Under this law, children who are eligible for special education services are entitled to Free Appropriate Public Education (FAPE) which, according to the IDEA, emphasizes special education and related services designed to be “provided at public expense, under public supervision, and direction, and without charge; meet the standards of the State educational agency; include an appropriate preschool, elementary school, or secondary school education in the State involved,” 20 U.S.C. § 1401(9). These unique needs may include extra services or modified instruction and can be found in the forms of either an IEP or a 504.

Mandated requirements for the OHI population include an Individualized Education Plan (IEP), which translate into:

A written statement for each handicapped child developed in any meeting by a representative of the local educational agency or an intermediate educational unit who shall be qualified to provide, or supervise the provision of, specially designed instruction to meet the unique needs of handicapped children, the teacher, the parents or guardian of such a child... [the] statement shall include: a statement of the present levels of educational performance of such child, a statement of annual goals, including short-term instructional objectives, a statement of the specific educational services to be provided to such child, and the extent to which such child will be able to participate in regular educational programs, the projected date for initiation and anticipated duration of such services, and appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether instructional objectives are being achieved. 20 U.S.C. § 1401(14).

The term 'educational performance' is not defined in IDEA. Instead, the Office of Special Education Programs (August 28, 2012), a branch of the United States Department of Education, directs school officials to consider both academic and non-academic development to determine eligibility on an individual case basis.

An IEP is used to provide the student with accommodations and modifications to the school curriculum. Accommodations can be defined as adjustments made in teaching methods and learning materials so that a child with special needs has the same opportunity to learn as a regular education student. Modifications are also ways of giving a child with special needs an opportunity to learn the same things as a regular education student, but are more often described as substantial changes in a child's educational program that will enable successful learning. Modifications often include such things as more time on tests and classroom assignments as well as reduced amount of items on homework and in-class assignments. Students must meet specific outlined eligibility criteria to receive services under IDEA.

If a student is denied services under IDEA, he or she may be found eligible under Section 504 of the Rehabilitation Act of 1973, a civil rights law. Section 504 is a Federal statute, enforced through the Federal court system, which protects qualified students with disabilities attending schools receiving Federal financial assistance. In other words, it allows public schools to provide accommodations so that all students can have access to school activities and to the curriculum.

Students with a medical illness often qualify for accommodations under section 504, but first a committee must meet to determine eligibility. A Domain meeting is held with parents or guardians and with the school's multidisciplinary

team to identify which areas, or domains, need to be evaluated and then to determine if a child is eligible for special education services. The areas that are generally considered include medical, social-emotional, general intelligence, academic performance, communication skills, and motor ability.

In order to be protected under Section 504, a student must be determined to: “(1) have a physical or mental impairment that substantially limits one or more major life activities; or (2) have a record of such an impairment; or (3) be regarded as having such an impairment.” Section 504 requires that school districts provide a free and appropriate public education to qualified students who have a verified medical condition that impedes their access to a general education and that substantially limits one or more major life activities.

The Section 504 regulatory provision at 34 C.F.R. 104.3(j)(2)(i) defines a physical or mental impairment as:

Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genito-urinary; hemic and lymphatic; skin; and endocrine; or any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.

Major life activities, as defined in the Section 504 regulations at 34 C.F.R.

104.3(j)(2)(ii), include “functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working”. The

determination of whether a student has a physical or mental impairment is made on the basis of an individual inquiry.

According to the United States Department of Education's Office for Civil Rights, students are further protected under Title II of the Americans with Disabilities Act of 1990 (ADA), which extends prohibition against discrimination to state and local government (including public schools) regardless of whether they receive any Federal financial assistance. The ADA Amendments Act of 2008, which became effective January 1, 2009, included an amendment to the Rehabilitation Act of 1973, affecting the meaning of disability in Section 504. In the Amendments Act, Congress provided additional examples of general activities that are to be considered 'major life activities,' including eating, sleeping, standing, lifting, bending, *reading, concentrating, thinking, and communicating.*

It is important to note these key concepts at this time as they help to guide an overarching question throughout this paper: Should children with chronic medical conditions automatically qualify as 'Special Education' students? Should they necessitate special education services if there is no limited impairment other than the inability to attend school? Is that a disability in its own right? These are important concepts to consider while addressing the needs and provision of academic services to students with chronic illness during periods of long-term hospitalization.

### ***Nature and Order of Presentation***

In the first chapter of this paper, I have provided an introduction to this self-study, including personal significance and background, as well as its purpose and

rationale. I have also identified key concepts relevant to this body of work.

In chapter two, I will provide a review of existing literature beginning with a history of Hospital Schools and an outline of the Public Laws and Acts throughout the past century that have shaped current policy and practice in the field. Next, I will discuss existing literature regarding the effects of chronic illness and long-term hospitalization on academic and psychosocial/emotional development. Finally, I will discuss how the provision of educational services corresponds to current health care policies and practices.

Chapter three will provide the conceptual framework and methodology behind this study. It will determine that missing from the existing literature is up-to-date literature, concurrent with recognition of the recent advances made in medical practices. These advances have led to increased survival rates in children with chronic illness, in turn creating a growth in the number of students requiring hospital-based educational services. Chapter three will also discuss the implications of budget cuts on health care provisions and the ramifications of these changes on this quickly growing population of children.

I will suggest that these increasing numbers require more extensive and specialized care from both healthcare and education professionals. Rationale for this study will propose the realization of current practices and the acknowledgement that as healthcare statistics are changing, the educational system and the services it provides struggle to keep up. Finally, I will pose my research questions.

In chapter four, I will include individual case studies. These studies will allow for a closer examination of the experiences of some of the hospitalized students with

whom I've worked closely over the past several years. In addition to an analysis of collected data, I will describe my personal experiences as an intern and my observations regarding current practices in major cities across the United States.

In chapter five, I will highlight some foreseeable limitations to my study and practice. Finally, I will conclude with a discussion of the incongruity of progression in regards to advancements in both the healthcare and educational services provided to chronically ill children. While medical progress has incited great change in the epidemiology of child health in the United States, chronic illness now accounts for the majority of childhood hospitalizations, presenting a challenge to educators in regards to the availability and provision of academic services to this population of students. Noteworthy, mirroring this unbalance of progression, is the prioritization of care within these two systems. There is no doubt that the healthcare field's primary concern is, and should be, the physical wellbeing of these children. However, greater collaboration with alternate services aiding in the healing process and updated policies in both fields would provide a more balanced approach, much like Fadiman's (1997) conjoint treatment, to caring for the whole child.

## **Chapter II. REVIEW OF EXISTING LITERATURE**

The purpose of this chapter is to examine the existing literature relevant to educational services for children with chronic illness, during periods of long-term hospitalization. Literature and studies from the perspectives of historical foundations of hospital schools, public laws and acts supporting children with disabilities, academic and psychosocial-emotional development, and healthcare practices and policies are reviewed. An effort is made to identify the role that school services plays in the lives of students living with chronic illness in the United States.

Research suggests that maintaining intellectual growth and development during periods of illness is considered to be an integral part of the treatment and healing process. However, although it acknowledges that with “a school age population in the United States of over 73.7 million...the number of chronically ill children is a large population (over 800,000 children) that thus far has not attracted much attention or support from the educational or political communities” (Wilson-Hyde, 2009, p. 47). Little information in the literature defines or supports current organization or operation of hospital-based school service programs.

A review of existing literature also suggests that while there have been significant advances in medical practices, children with chronic illness are at increased risk for academic and psychosocial difficulties. It is believed that school services can ameliorate some of these difficulties by providing continuity between a child’s hospital room and his or her home environment. Schlozman (2002) maintains that school is a “luxury that quickly departs when a child falls dangerously ill. In this sense, school becomes a refuge, and educators should understand their crucial role in



protecting this sanctuary” (p. 83). For many hospitalized children, this refuge can symbolize a return to, or at least glimpse into normalcy.

Harris and Farrell (2004) cite a “constellation of factors” which put students with chronic illness at risk for significant disruption to their education. These disruptions can occur as a single, long-term period of time out of school that may derive from a relatively uncomplicated accident or illness; repeated interruptions associated with serious chronic illness, which can lead to a fluctuating pattern of school attendance; or the effect of degenerative/terminal illnesses where a child may develop associated cognitive problems leading to reduction in academic ability over time, (p. 14).

Brown and DuPaul (1999) explain, “it is often the interaction of health variables with other contextual (e.g. family and school), developmental and environmental factors that are of central importance in predicting children’s adaptation and adjustment to the illness process” (p. 176). Therefore, it is imperative that we recognize the cognitive, social-emotional and environmental factors that aid in predicting a child’s relationship to chronic illness.

### ***A History of Hospital Schools***

Although I was able to find little, if any information in the literature regarding the history of hospital-based school service programs throughout the United States, I was able to obtain a significant amount of research on the development of alternative home and hospital education programs in America’s public school systems. A large

metropolitan city in the Midwest, Chicago serves as an appropriate example for the history and development of Hospital School services.

Chicago, Illinois was a pioneer in early hospital school programs, laying the foundation for the provision of educationally-based services to children with chronic illness as early as 1893, with the opening of The Home for Destitute Crippled Children.

By-laws for the Home included providing all children with two hours of academic instruction each morning. The goal of this service was “to help on a healthy, purposeful growth, thus preventing as far as possible the disease of mind and character which seems sometimes to be the natural outgrowth of a diseased body” (Rankin, 1993, p. 8).

In 1899, the wife of the President of the Chicago Board of Education convinced her husband to adopt the Home’s hospital school program. The school quickly became part of the Chicago Public School system, the teachers salaried and the students eligible to receive the same benefits offered to all other students in the city.

In the early 1900’s, Chicago saw advances in the special education movement, with an overlap of medicine and education, “each at times venturing into the domain of the other. Both were under the constant pressure of reformers and special interest groups to improve the lives of children. These societal forces resulted in the development of needed services, which were provided by both medical and educational practitioners. The result was the improvement of services to crippled children by the Chicago Public Schools. This was followed by legislation which

allowed other districts to follow suit. Special programs expanded and were adapted by educators as innovative expressions of an awakening public interest in the welfare of children with debilitating health conditions” (Rankin, 1993, p. 42).

During this time, medical facilities catering to children had multiplied and health care vastly improved. Prominent organizations encouraged the development of various hospital-school programs in hopes of meeting the educational needs of the growing number of hospitalized children throughout the city of Chicago. At first, volunteer teachers from Chicago Public Schools provided after-hours instruction, however after just a short period of time, hospital administrations acknowledged the need for permanent programs and requested the Board of Education provide full time instructors. By 1918, hospital classrooms were created so that when appropriate, children could benefit from group instruction and social contact with other students.

Rankin (1993) details the expansion:

During the school year 1939-40, five hundred patients a month were provided with an educational program. The annual report of that year noted three principal purposes attached to the hospital school programs: to continue general educational development; to have therapeutic value; and to be of some vocational assistance. Teachers requested and received a record of school progress from the home school. This included grade placement, subjects to be studied, textual materials, and information regarding special abilities and needs. When leaving the program, a record of work accomplished was returned to the home school. The related services of speech, occupational

therapy, and counseling were offered through cooperative efforts of private and public providers (p. 63).

After World War II however, the mid 1900's saw a decline in availability of funds and therefore a decrease in opportunity to provide educational services to all hospitalized children. Declining revenues prevented the hiring of additional teachers, limiting all students to a five-hour maximum of instruction per week. Associated problems arose including conflicting viewpoints regarding the appropriate certification of hospital teachers, as well as coordinating attendance and credits with students' home schools (Rankin, 1993).

Unfortunately, by the late 1900's, the number of hospitalized children in the City of Chicago not receiving proper educational services "increased to disgraceful proportions. Insufficient and unqualified staff accompanied by organizational constraints further compounded the problems. Difficulty in receiving credit for academic work, and failure to fully implement the individualized educational programs of special education students were major concerns" (Rankin, 1993, p. 99).

In 1989, according to Rankin (1993), a significant system reorganization was made in an effort to increase efficiency and keep district costs down. All hospital teachers were reassigned from individual Hospital schools to a citywide service unit known as the Home and Hospital Instruction Program.

Today the Chicago Public School's Home and Hospital program (HHIP) provides access to educational instruction, by a Special Education-certified Chicago Public School teacher, to students who are absent for ten or more consecutive school days due to a medical condition. According to the HHIP website, there are

approximately fifteen teachers currently providing instruction in fifteen hospitals and treatments centers throughout the city of Chicago. Students who do not attend Chicago Public Schools but are hospitalized in the city of Chicago are not eligible to receive these services, (CPS Home/Hospital Services, 2010).

### ***Significant Laws and Acts***

Literature acknowledges a need for the provision of educational services to children who are unable to attend school because of chronic illness. However, very little information exists in regards to the actual implementation of these services. Hospital schools are mandated and regulated throughout the United States by federal laws, state regulations and citywide policies (Breitweiser and Lubker, 1991) but in actuality there exists a deep rooted controversy between the medical and educational communities concerning the provision of special education services to children with chronic illness. While historically, education law “has limited access to special education-related services...the medical community has argued that strict eligibility definitions often were discriminatory to children whose health care needs were not being met at school” (Koenning, Benjamin, Todaro, Warren & Burns, 1995, p. 207).

Wilson-Hyde (2009) argues that “public education in America has not historically addressed the needs of students unable to attend school due to medical conditions, but [that] federal policy changes since the 1960’s have made some progress in defining the responsibility of school systems to the student population of chronically ill children” (p. 48).

Beginning with the Elementary and Secondary Education Act (ESEA) of 1965 and following with the provisions in No Child Left Behind (NCLB) of 2001, national education policies began to require that educational services be provided to this population of students. In fact, according to “federal and state law and Joint Commission standards, hospitals that admit pediatric and adolescent patients have no option about whether to provide some kind of school service” (Breitweiser and Lubker, 1991, 34). The operative words, unfortunately, are ‘some kind’.

Today, many children with chronic illness are eligible for special education services under the Individuals with Disabilities Education Improvement Act of 2004 or through educational accommodations under section 504 of the Rehabilitation Act of 1973. However, “states have some discretion in their interpretation of ‘special needs’,” (Thies, 1999, p. 392). For instance, the implementation of an Individual Educational Plan (IEP) is “left to the state educational systems. States provide various options for students unable to attend classes...but the access and quality of service varies from state to state, and guidelines for the education of chronically ill children are inconsistent across the nation” (Wilson-Hyde, 2009, p. 48). It is because of this loophole, that hospitalized students often do not meet the classification criteria. Thies (1999) explicates, “federal laws prohibit discrimination and affirm the need for accommodation, but fail to provide specific guidance regarding identification of this population.” (p. 394). Currently, there is no legal mandate that exists to serve *all* children who suffer from chronic illnesses.

### ***The Effects of Chronic Illness and Hospitalization on Academic Development***

It comes as no surprise that children with chronic illness experience more academic difficulty than their healthy peers. Thies (1999) attempts to analyze this reality:

The combination of chronicity, absence, and side effects of illness and treatment are subtle, but the cumulative effect is potentially damaging. Falling behind academically leads to catching up, and catching up takes time away from keeping up. Self-confidence and achievement motivation are undermined. Educational deficits are more likely manifested in subjects that build on previous knowledge, such as mathematics and foreign languages. Marginal students and those with established learning disabilities are particularly vulnerable (p. 396).

Kagen-Goodheart (1977) suggests that “academic competence often takes on added meaning as it may represent the only area where there can be a feeling of control and a sense of accomplishment” (as cited in Isaacs & McElroy, 1980, p. 319). Still, forty-five percent of students with chronic illness report falling behind in their schoolwork (Thies, 1999, p. 394).

Motivation becomes an issue for a number of reasons. Aside from extenuating risk factors, “disease symptoms or side effects of treatment regimes can induce fatigue, lethargy, irritability, or other physiological states” (Shaw & McCabe, 2007, p. 78). However, Madison & Raphael (1971) suggest that the chronically ill child’s definition of his or her own intellectual development “largely depends on the extent of interaction with a sufficiently stimulating environment” (as cited in Isaacs & McElroy, 1980, p. 319).

While chronic illness is often associated with cognitive morbidities, many children stigmatized with ‘learning disorders’ resulting from their disease or that are associated with the adverse effects of treatment for their disease, suffer little to no impairment in their ability to learn. Their “disability” lies only in their inability to attend school regularly. Therefore, academic services provided to chronically ill children during periods of hospitalization are often most effective when they target the many contextual factors in the child’s environment that affect his or her motivation.

### ***The Effects of Chronic Illness and Hospitalization on Psychosocial/Emotional Development***

Existing literature suggests that from a psychosocial/emotional standpoint, the normality of school is therapeutic for students during periods of long-term hospitalization. Brown & DuPaul (1999) explain that as chronic pediatric illnesses have “yielded to improved medical advances and as infectious diseases have been eradicated, greater attention has focused upon the role of psychosocial factors in health and illness” (p. 175).

Ultimately, regardless of whether or not he or she is sick in the hospital, a child’s development does not cease. Schlozman (2002) posits that because of this, those who work with medically ill students should “ensure that these children continue to grow and learn emotionally,” (p. 82). Overall, well-being can improve the child’s life, both physically and psychologically.



Sullivan, Fulmer and Zigmond (2001) warn that not only are these children “vulnerable because of the medical aspects of the disease, but they are also vulnerable to secondary psychosocial effects of chronic illness (p. 12), making it important to find ways to minimize these effects while facilitating positive academic experiences.

Hospital educators can play a large role in this facilitation by serving as a familiar connection between the world outside of the hospital and the world within; “The teacher is there to stimulate children through using her knowledge of the curriculum needs of a child. Because of this knowledge, she can act as a catalyst and interact with the children to enable learning to take place” (Wiles, 1987, p. 640).

Spinetta et al. (1976) remind us that by lowering our expectations, we are telling a child that he is “doomed”. By denying the child an opportunity to engage in developmentally appropriate goal-oriented behavior, we are only reinforcing feelings of hopelessness; likely interfering with the child’s ability to cope with his or her illness. School represents the continuation of normal life, and can also help to reestablish routines of daily living. As hospital teachers aid in the fostering of psychosocial development through educational services, they serve as an anchor in the lives of the children they teach. The ways in which they approach the education of chronically ill children can significantly affect the students’ attitudes and behaviors towards school, and towards life in general.

***Chronic Childhood Illness, Long-Term Hospitalization and Current Health Care Policies and Practices***

Children with chronic illness represent a unique population in the United States, as they exist within the intersection of the American Healthcare and Education systems. However, a review of related literature reveals an absence of current discussions between educators and healthcare professionals regarding the impact of children's health conditions on their ability to learn. Thies (1999) attempts to explain this absence by arguing, "when children are acutely ill, academic performance is not perceived as a priority. When these same children appear well, health is not perceived as a factor in their education. It is often unclear who bears the responsibility for addressing the actual or potential impact of a health condition on learning" (p. 392). The question becomes one of accountability.

Baird and Ashcroft (1984) explain that there is "a wide variation among states in the minimum number of days a student must be absent before becoming eligible for home and hospital instruction" (p. 99). Literature finds that once a child is deemed eligible for school services in a hospital environment, the amount of time he or she spends with a teacher is also varied, generally considered inadequate, and often lacking continuity. An additional barrier is the non-overlapping service systems of health and education that prevent a successful school experience for a child with chronic illness. Too often, educators lack knowledge of specific illnesses and their affect on educational performance, while health providers fail to communicate the medical needs of their patients. An attempt to bridge this disconnect, making clear the educational implications of a child's health-related disability, would most certainly effect his or her school experience.

Literature suggests that “a broadening of the “med-ed” gap,” (Koenning, Benjamin, Todaro, Warren & Burns, 1995, p. 207) continues to effect the provision of care for chronically ill children and that simultaneously, the management of a sick child continues to be viewed first as a medical phenomenon, with secondary attention paid to his cognitive, emotional, and social development. There are several questions that must be resolved regarding both categorization practices as well as the functioning of current academic service delivery systems. First and foremost, policy action is needed to address reforms in an attempt to answer these questions.

## **Chapter III. CONCEPTUAL FRAMEWORK AND METHODOLOGY**

### ***Conceptual Framework***

After a review of the existing literature, I cannot help but wonder: How have our educational services for chronically ill children changed? Have they evolved with the times? Are our current programs meeting the needs of these students? Have our priorities shifted or have we simply given up?

Ultimately missing from the existing literature is up-to-date literature, concurrent with recognition of the advances in medical practices, the increased survival rates in children with chronic illness, and in the number of students requiring hospital-based educational services. It is apparent that a more integrated approach, with participation from both the education and healthcare communities is necessary in order to provide successful educational programming for children with chronic illness. But how?

Although it has been nearly thirty years since Baird & Ashcroft (1984) wrote of the inadequacies in administration of hospital services, today's provision of services still appears to need modification in order to ensure response to individual student's needs. Thies (1999) wrote, "unlike other disabilities, the course of illness represents a roller coaster of changing needs, moving between acute medical crisis and long-term management of health. Children with chronic illness often fall between regular and special education, making do with accommodations until problems that could have been anticipated can no longer be ignored" (p. 396). However, it seems that no child, especially one who is chronically ill, should need to "make do" with educational accommodations.

Walton (1951) provides a historical account of the Ann Arbor University Hospital's nursing program, which at that time required nursing students to complete an internship program which included training in the area of tending to emotional and intellectual needs of children with chronic illness. After learning of this innovative and revolutionary practice, I cannot help but question: What happened? Why do we appear to be taking steps backwards?

These issues call for an integrated and comprehensive redirection of care. Successful implementation of educational services provided to these children must depend on a flexible, interdisciplinary approach that equally addresses their medical, psychological, and educational needs. There must be a realization of current practices and an acknowledgement that as statistics are changing, the educational system- still lacking flexibility and established policy- is simply unable to keep up.

### ***Research Questions***

Herein lies the central issue of this study and the questions I hope to answer: how do educational services support development in children during periods of long-term hospitalization? What amendments need to be made to the provision of educational services in order to better serve this growing population? How can health care and educational systems work together to better provide these services?

In the process of analyzing my own observations, and in conjunction with a review of literature on hospital school services programs, I will attempt to provide suggestions for meeting the academic needs of young children affected by chronic

illness. It was my intent to do so while maintaining a belief that if these needs are met, all children have the ability, and the right to function at their maximum potential.

### ***Self-Study Methodology***

In their article regarding guidelines for autobiographical forms of research, Bullough and Pinnegar (2001) discuss the notion that who the researcher is, is fundamental in regards to what the researcher does; “that to study a practice is simultaneously to study self: a study of self-in-relation to other” (p. 14). Mirroring my intentions for this project, “the aim of self-study research is to provoke, challenge, and illuminate rather than confirm and settle” (p. 20). However, the authors warn that self-study researchers must negotiate a balance between history and biography. This means that while one must inevitably acknowledge the role of ‘self’ in a project, “such study does not focus on the self per se but on the space between self and the practice engaged in. There is always a tension between those two elements, self and the arena of practice, between self in relation to practice and the others who share the practice setting” (p.15).

If ever there was a measure of the role of self in the study of a practice, this research thesis might just be it. A couple of years ago, I might have exaggeratingly stated that this project was my life. Only this past February, it actually *became* my life.

If someone had told me in the Fall of 2009 that I’d still be working on my thesis three years later, I’m not sure I’d have believed him. I’m also pretty sure I’d have questioned whether to start it in the first place- but I’m so very glad that I did.

When I began this project, never once did it cross my mind that I would become a part of the population I was studying, that I could ever relate so profoundly to my students.

At the beginning of this year I was diagnosed with an extremely rare form of cancer called Erdheim-Chester Histiocytosis. For the following several months, I was forced to step back from my work, to focus solely on my most important job: surviving.

When I first became sick, it was necessary to leave the Midwest and return home to Los Angeles to live with my Mom, through what turned out to be the most difficult year in both of our lives. Now-- post-diagnosis, post-radiation and chemotherapy and hip reconstruction surgery, post-leaving the life I'd worked so hard to build for myself and post-beginning to start anew-- I am left with a healing body, an attacked yet hopeful perspective and sense of gratitude, and an absurdly large stack of medical bills.

When I interned with the pediatric hospital's school services department, the majority of my students had cancer. Not because there was some sort of epidemic in the city, but simply because these are the kids who usually spend the most time in the hospital. These are the kids who are out of school for greatest number of days. These are the "frequent fliers," as the oncology nurses who became second mothers endearingly called them.

During my internship, as close as I got to my kids and their families, I had no idea what they were really going through. I couldn't have. And although I celebrated my patients being discharged with a rare combination of hope and fear that I'd never

see them again, I had no idea what their lives would be like once they left the hospital. Not that I didn't before, but even more so now, I think about them every day.

This self-study is grounded in my own personal reflections from three very separate perspectives: first as an intern in the pioneering hospital-based School Service program of a prominent pediatric hospital; next as a graduate student constantly dissecting the current political system and its seemingly intransigent problems, often to no avail; and most recently and certainly most unexpectedly, as a cancer patient, examining the entwining of learning and illness from the other side of the stethoscope. As I've come to witness the collision of my own healthcare and education, my work on this project has functioned as "healing art" practiced alongside the UCLA oncology center's more traditional medicinal practices.

Over the past year, I've spent more time in a hospital than I could ever have imagined and have witnessed firsthand why Fadiman (1997) described Lia Lee's doctors as 'imperfect healers'. Attempting to maintain a self-study methodology perspective- and months after my very first night in the hospital, where I was incorrectly told that my 'working diagnosis' was Multiple Myeloma, a bone-marrow cancer with an incomparably terrifying prognosis- I began reading my medical records:

*This is a 27-year-old female who prior to the current events had no past medical history, who is presenting after an extensive workup for fever of unknown origin, and found in the ED to have multiple lytic lesions on CT abdomen and pelvis, posterior iliac crest, femur and ribs, with apparent pathological fractures in the area that the patient reports point tenderness. The Medicine Service was called*



*for admission and Hematology-Oncology was consulted for a possible malignancy diagnosis. The patient and the patient's parents were informed of the working diagnosis and an extensive discussion was had regarding the subsequent workup. The patient and the family were visibly distraught, and concerned, and anxious over the news and multiple questions they had were answered compassionately and appropriately.*

I didn't read much further. Medicine, as it is taught in the United States, writes Fadiman (1997), "does an excellent job of separating students from their emotions. The desensitization starts on the very first day of medical school, where each student is given a scalpel with which to penetrate his or her cadaver... The emotional skin-thickening is necessary- or so goes the conventional wisdom- because without it, doctors would be overwhelmed by their chronic exposure to suffering and despair. Dissociation is part of the job" (p. 275). Imperfect, yes. But they saved my life.

Outside of the hospital environment, it's generally accepted that youth and health are meant to be synonymous. Only as a young adult in the oncology ward, I often felt like a child. I was almost always the youngest patient in the chemotherapy center. In fact, I'm the youngest person my doctor has ever treated with this disease; the majority of patients with my form of Histiocytosis are over 50. Suddenly, that I'll sleep-when-I'm-dead twenty-something mentality I'd come to rely on became significantly less efficacious when at 27 years old, I was forced to confront my own mortality.

When I had completed treatment, and was given the go-ahead to resume a somewhat "normal" life, I began to write again. Only as much as I attempted to

separate my self from my work, to disassociate, even to compartmentalize all that happened, I found it hugely difficult. Perhaps it's a good thing I didn't go to medical school. Perhaps it's a warning sign with regards to my plans for future practice. Regardless, I am wholeheartedly in this project and have in fact, unintentionally come to embody the balance struggle of the self-study methodology. It is because I wish to keep history and biography purposefully independent of one another, that I chose to share my own story in this section only. The rest of the study will focus on the arena of practice, and on those with whom I shared the practice setting.

### ***Participants***

Aside from my own, this study includes individual case studies, allowing for a more in depth examination of the experiences of three hospitalized students with whom I worked closely throughout my internship. During this time, I cultivated relationships with these patients and their families and witnessed their positive academic progression and associated developments. The participants' chronological ages ranged from four to ten.

The patients discussed in these case studies were each hospitalized during my internship, sometimes more than once, for varying lengths of time, and for the following primary conditions: Acute Lymphocytic Leukemia; Ewing's Sarcoma; and Hypoplastic Left Heart Syndrome. Details of these conditions and their associated academic, psychosocial/emotional and physical side effects will be discussed in detail in each case study. While the accounts are factual, each of the children in chapter four has been given a pseudonym, used to protect patient identity.

### *Procedures*

This study is based on the reflections of my observations during my time as an intern with the school services department of a pediatric hospital, in a large metropolitan mid-western city. These reflections were recorded in daily journals, compiled between August 2010 and January 2012, and are based upon the observations and interactions I had with the patients, their families, and various staff members of the hospital. Informal conversations, relevant medical information, and running records of general, and more specifically academic performances were included in these journals. Research was also conducted in the form of personal and telephone interviews with teachers and administrators from several hospital school service programs throughout the country.

On average, students were seen two to three times a week for sessions of about one hour, for the duration of their hospital stay. Patients were either visited bedside or able to work in the hospital's classroom. Interactions included individual and group tutoring, casual conversations with patients, parents and other family members, informal work with hospital staff, as well as participation in weekly interdisciplinary rounds. This self-study is a collection of this research, these anecdotal interactions and my observations.

#### **Chapter IV. ANALYSIS OF THE INFORMATION, MATERIAL DATA**

The purpose of this chapter is to provide a closer examination of the experiences of chronically ill school-aged children during periods of long-term hospitalization. It includes a detailed description of a hospital school as well as individual case studies of a few participating students. Although I did receive Institutional Review Board (IRB) approval from both the university and the hospital, as well as parental consent from each participant's parent or guardian, these individual studies are based solely on a reflective review of my journals, observations, and experiences between the dates of August 2010 and January 2012. In addition to an analysis of this collected data, I will describe my personal experiences as an intern in a pediatric hospital-based school service program and my research of current practices in other hospital school environments.

A review of existing literature suggested the notable absence of up-to-date information, concurrent with recognition of the recent advances made in medical practices. These advances have led to increased survival rates in children with chronic illness, in turn creating a growth in the number of students requiring hospital-based educational services.

An analysis of current program availability and function necessitates a significant advancement in the development and implementation of school services programs to students with chronic illness during periods of long-term hospitalization. Not only is school one of the most normalizing factors in a young person's life, cognitive development helps to promote and maintain a healthy emotional state. Additionally, continuing with education during hospitalization provides a sense of

hope and allows students to focus on something other than their illness.

The first section of this chapter will attempt to answer how educational services can support development in children during periods of long-term hospitalization by detailing the overall experience and success of an in-patient, hospital-based educational services program.

### *Site Overview*

For the purposes of anonymity, the hospital in which I interned will be referred to simply as ‘The Children’s Hospital’ throughout the discussion of this study. This renowned institution, regarded as one of the top pediatric hospitals in the nation, is guided by the belief that all children need to grow up in a protective and nurturing environment and should be given the opportunity to reach his or her full potential.

The Children’s Hospital is located in an urban neighborhood in a large, metropolitan Mid-Western city. The hospital practices a compassionate, family-centered approach to care and offers a multitude of support services designed to help patients and families cope with the unique stresses associated with being in the hospital. Staff activity coordinators provide a variety of programs and services for patients, siblings and families in both inpatient and outpatient settings. Specially trained volunteers enhance the hospital experience by supporting play and learning experiences, both at the bedside and in the hospital’s ‘Family Center’. The Center is devoted to inpatients and their families, offering amenities including playgroups, a teen lounge, a business center and a quiet room for relatives. Other family services

provided to patients and their families include Spiritual Care, Social Work, Parent Support, Grief Support, Creative Art and Music Therapy, and Child Life.

In a majority of pediatric hospitals, the program most closely resembling a School Service department is Child Life. Child Life Specialists are trained professionals who work to help children and their families overcome serious illness. In a hospital setting, the Child Life team promotes effective coping through play, and self-expression activities. They provide emotional support and encourage optimum development of children facing challenges related to healthcare and hospitalization. This year, the Child Life Council is celebrating its 30th anniversary, with a membership that has grown from 235 in 1983 to nearly 5,000 members in 2012.

Having worked closely alongside Child Life during my internship with School Services, and at times overlapping with specialists, I've become very familiar with their vital role in the pediatric hospital environment. Although I acknowledge the necessity for the services they provide, I do believe School Services can and should have a separate and comparably important place in the lives of children with chronic illness during periods of long-term hospitalization.

Child Life Specialists, while indispensable in a pediatric hospital environment, focus primarily on the present, on the time a child spends in the hospital. They have to; it's their job. School Services on the other hand, working in addition to and alongside a successful Child Life program, might aid in satisfying the child's (and the parents') need for hope, for the possibility of a future outside of the hospital.

In the United States, ambitions for the future are often conceptualized through, and associated with the idea of the pursuing of an education. Correspondingly, this notion rings true in even the darkest of hospital rooms. I've witnessed numerous times, the effects of a teacher saying to a child in the hospital, "hey, time for school, gotta learn those fractions!" What the child hopefully hears, and the teacher desperately prays, is that he better learn those fractions because one day, he's going to get out of there, he'll be back in his own classroom, with his friends, and they are all going know fractions. So he'd better practice now. With those words, that child and his family are given a sense of hope. The *normalcy* of a third grader needing to learn fractions brings hope.

### ***The Children's Hospital's Educational Services Program: School & Learning***

The Children's Hospital School Service Program is a philanthropically funded initiative concerned with education for its hospitalized patients. The hospital acknowledges that chronically ill children are a population at risk for educational and developmental delays resulting from their illnesses and disrupted schooling. The program provides certified teachers and trained tutors who help patients with school assignments or educational projects geared toward individual needs. In addition to the educational benefits, this program has been proven effective in normalizing a child's hospital experience.

Aside from the program's director- whose myriad of duties rival those of an entire department- and her intern, the tutors are all volunteers; some of whom work in other departments throughout the hospital and who chose to give up their lunch hours, or to stay late one evening each week, to work more closely with patients. Each

volunteer must go through a rigorous training including learning the ins and outs of the hospital environment. He or she must also pass a competency validation regarding the safety and transporting of patients. Training goes so far as to include an understanding of and proficiency in the handling of medical equipment, as tutors are often left alone with patients and must know what to do in case of an emergency.

The program seeks to provide developmentally appropriate activities to all school-aged patients and siblings. In addition to instruction, children are invited to explore materials in the classroom during designated hours or by appointment. Activities and resources available are extensive, with access to technology, basic supplies, and hands-on manipulatives in many subjects. Ideally before services commence, the program will contact a child's school to coordinate instruction and whenever possible will have that child's work sent in so that he or she remains on target with peers.

The program director serves as an advocate for children and parents, communicating with their primary schools when necessary, and providing resources at the local school and district levels. Although it is unclear as to whether this is part of her job description, the director also acts as liaison with the city public school teachers assigned to the Children's Hospital.

After becoming accustomed to the hospital's school program and witnessing the incredible services the director and her volunteers provide patients and families, I couldn't help but wonder: What's the catch? Why wasn't this happening in every pediatric hospital? The answer, I discovered was several layers deep. To begin, I was reminded that neither the patient's families nor their school districts pay a penny for



these educational services; not every hospital could manage to fund such a program. Secondly, school services function as an important part of the umbrella of family services offered to each patient. In order for the program to work as well as it does, the program's contributions must be recognized as a vital part of the overall success of the hospital. Lastly, and perhaps 'the catch', while the program is run by a certified teacher and all volunteers are properly trained in providing educational services, the program itself is non-accredited. This means that while the public school district's hospital school program may credit students for hours spent working with a teacher, and may administer standardized tests, students who participate in a hospital-based school service program are unable to receive any actual time-credits.

It could certainly be argued that this matters significantly less in the lower grade levels but is an understandable concern for a high school senior hoping to graduate alongside her classmates. The next question to be asked is a difficult one: given the circumstances, does it really matter? The answer, I've come to believe is that it depends on the individual student. However, in general, the benefits of the experience of school services for chronically ill students during hospitalization greatly outweigh the negative afterthoughts of time-credits, grades and standardized testing.

### ***The Role of the Intern***

It's always difficult explaining to outsiders how much I loved working in a children's hospital. "But isn't it depressing?" friends would ask, "I don't know how you do it". Sometimes, it was depressing. Sometimes I'd walk home after a long day

at the hospital and just wanted to cry, thinking about how *lucky* I was to be able to walk home. Sometimes I did cry.

But there was also a lot of laughter. I *loved* seeing young patients reprimanded by nurses for riding their IV poles down the hallways like skateboards. I loved sitting in interdisciplinary rounds and hearing about a child getting switched from one room to another because he and the boy in the adjoining room started a food fight through the doorway. I will never forget the social worker who promised her patient a one-on-one egg and spoon race around the hallways of the seventh floor, when she was finally strong enough to get out of bed. I *loved* watching them race.

These stories, among so many others, help to remind me that more than anything else, these are just kids. If you take away the tubes and the lines and the casts, they're kids. And when you sit down and read a book to one of them, you're just reading to a kid.

My first week as an intern felt like a test of strength. Only it wasn't just my multitasking skills or my emotional tolerance that were tested; apparently my 'prankability' would also be challenged. On my third day as an intern I was assigned to work with eight-year-old Sean, who I'd been warned often attempted to finagle his way out of having to do homework. This young man must have heard that there was a new intern on the ward and cleverly, although to this day I'm not sure how, managed to convince another 8 year old child to switch beds for his hour of school. I hadn't met either boy before and it wasn't until Sean's roommate returned to their room several minutes into our session and exclaimed, "Hey man, what are you doing in Sean's bed?" that I realized I had been 'punked', pediatric-hospital style.

Aside from working one-on-one or in small groups with patients, either bedside or in the hospital classroom, I was responsible for assisting in curriculum planning and project development, preparing and maintaining educational materials for tutors, scheduling and supervising volunteers and attending multidisciplinary rounds, along with nursing, social work, child life, case management, and pastoral care, several times each week.

These multidisciplinary rounds were perhaps the most significant difference between my role with the school service program and the role of a public school district teacher assigned to the hospital. In these meetings, I was able to gain invaluable information about the medical, psychosocial, and emotional development of each child, helping me to build upon my knowledge of their individual needs. The benefits of sitting in these rounds were unmatched and after having participated in many, I cannot fathom walking blindly into a student's hospital room without such advantageous information.

### ***Case Studies***

I remember one day in particular, an otherwise seemingly uneventful yet equally maniacal day in a pediatric hospital, I was waiting for an elevator to take me from the oncology floor back up to the hospital's classroom. Just a few steps to my right, I heard a young mother on her cell phone, probably speaking to close friend. I wasn't trying to listen but you unintentionally overhear a lot in the hallways of a hospital, and I heard her say something to the effect of "I just don't understand. I look around at these other kids up here and they clearly HAVE cancer, they're really sick.

She doesn't look like them, she doesn't look sick. How can she be like these kids?" I'm not sure what it was about that day, that woman, that phone call, but her words made an impact. The story of this young mother continues to remind me that when illness comes into play, especially in the lives of young people, we are awakened to the reality that everything is fragile, that everything can change in an instant.

### **JONAH, Age 5**

*“Protective Isolation- for patients whose immune systems have extra difficulty fighting off infection, wash hands, wear gown and gloves and mask, absolutely no sick contacts.”*

### **Background Information**

Jonah is a five-year-old Caucasian male. He has short blond hair and blue eyes and appears slightly smaller than average for his age, in both height and weight. His skin is rather pale, his eyes slightly sunken, and he has several small, fading bruises on his arms and legs.

Jonah is an only child and lives in a suburban neighborhood several hours from the Children's Hospital with his mother and father. He has completed two years of preschool and is enrolled in his local Kindergarten but has been unable to attend most of the academic year. He says that he enjoys school, particularly recess and math, and that he likes his teacher very much. Jonah has many developmentally appropriate toys, games and books in his hospital room. He loves superheroes and is almost always wearing spider- super- or batman pajamas.

### **Medical History**

Jonah was recently diagnosed with Ewing's Sarcoma of the hip. This rare bone cancer is most often seen in children and adolescents and typically requires systemic treatment including chemotherapy, radiation, and often surgery. He has recently been hospitalized for neutropenic fever (associated with a low white blood count after undergoing chemotherapy). Jonah has a central line in place through which he receives his medicine and fluids.

### **Questions For This Study**

How is the illness effecting his development other than disabling him from attending kindergarten?

Is his cognitive functioning different than it would be if he hadn't undergone chemotherapy and radiation?

Is he on target and if so, will he remain at this level or will there be further cognitive repercussions from his illness and/or hospitalizations?

### **Current Functioning**

Jonah's affect is upbeat and although he is unable to leave his hospital room and is attached to monitors, he moves actively and freely around his bed. Whenever I enter his room he is most often engaged in an activity; I've rarely found him to be sleeping in the middle of the day. He engages well with hospital staff and with his parents. Jonah appears to be hitting all developmental milestones and is functioning at an age appropriate level with regards to his cognitive, behavioral and emotional development. Jonah is sociable, inquisitive, and follows directions well. He genuinely seems to enjoy 'school time'.

### **Present Concerns**

The main concern for Jonah is that he is lacking any significant normalization during his hospital admission, other than school services. He does have books, games and toys from home but has mentioned that these are his hospital toys, so there is a clear association already in place with being sick and playing with these particular items. The goal is to keep him as engaged as possible, as often as possible, to ameliorate the effects of isolation from normalcy.

### **Informal Assessment and Developmental Progress**

Jonah consistently had homework from his kindergarten teacher that we often worked on together. The work generally consisted of worksheets on which he would practice his letters and numbers. Jonah is beginning to write words and to sight-read. There was often extra time after completing his assignments so I would usually bring either a puzzle or an art project to work on together. Jonah enjoys art and his fine motor skills are well developed enough to complete most projects on his own. He can cut with a pair of scissors and holds his pencil (almost) properly, with his dominant, right hand. When working on puzzles, Jonah uses trial and error and typically remains patient and calm throughout the process. He seems to find joy in successfully completing them and demonstrates pride in his work.

### **Summary of Reflections and Recommendations**

During one tutoring session, I was sitting on the edge of Jonah's bed reading a book to him when several doctors walked through the door. Although I had become very used to dealing with nurses, I rarely came in contact with doctors. In fact, if a doctor came into a patient's room during a 'school hour', it was protocol for me to step outside until he or she was through.

On this particular day, the doctors came in and asked if he was ready and whether his parents were nearby. I explained that we were just finishing up our session and that his mom should be back shortly. I don't know if they thought I was a social worker or a child life specialist, or whether it mattered at the time, but since I was there then and no one else was, I guess they figured I'd do. They asked me if I was okay staying and holding him while they removed his central line.

I looked at Jonah, his eyes welling up with tears, this wasn't the first time he'd had this done and he was scared. Of course I'd stay, but did they want to come back in a few minutes once his mom had returned? They didn't.

The doctors had come to remove Jonah's central line. A central line is a tube that is surgically inserted into a large vein, usually in the chest, making it easier to access the bloodstream. The outside end has several ports that connect to IV tubes. These tubes can be used to infuse medicine, blood, or bone marrow into a vein, also be used to draw blood from the vein for blood tests. With a central line, you do not need to have a needle stick each time you get IV drugs. This is optimal for kids that are inpatient for extended periods, so they don't have to be poked multiple times a day. Some kids have a PICC line instead, which is inserted into their arm, and is less invasive.

So, would I stay and hold him? Of course. They doctors raised the bed, with both of us now fully on top of it, and asked Jonah if he was ready. He began to cry. I of course had no idea what was about to happen; I had never seen a central line taken out. They removed the dressing and sutures, counted one, two, three and yanked it out in one quick motion. I was... shocked.

After just a few moments of weeping, Jonah quickly returned to his normal cheery self and proclaimed, “It wasn’t actually such a big deal!” (A comment I’m sure he had heard his parents say several times in an attempt to calm him down). This incredible ability to snap back from such a terrifying experience and to compartmentalize so quickly, separating the situation which brought him to tears just minutes before, helps me to believe that with the necessary medical treatment and a well supported return to school, Jonah will be able to maintain his on target development and will continue to hit appropriate associated milestones.

#### **NEAL, Age 4**

*“Contact Isolation- for patients with illnesses that are carried on hands or objects, no special air handling, wash hands, wear gown and gloves.”*

#### **Background Information**

Neal is a four-year-old male. His father is Caucasian and was born in the United States and his mother is from the Philippines. Neal is an only child and lives at home with his parents and maternal grandmother. He is very small for his age, but with a large round belly and swollen rosy cheeks. He has tan skin, thick dark hair and dark brown eyes. Upon first glance, he appears to be ill and it is apparent that he does not function at the level of a typically developing four-year-old. Neal’s mother and grandmother are his primary care givers, his father visits when he is able. The family lives several hours from the Children’s Hospital. Neal’s father speaks only English, while his mother is bilingual in English and Tagalog. His Grandmother speaks primarily Tagalog but understands a few words in English. When she is alone with



Neal, she has difficulty communicating with hospital staff. For this reason, Child Life has prepared a picture chart for guests to use in order to communicate with her both why they are there and what they will be doing with her grandson.

Neal is a happy child, despite sometimes appearing uncomfortable. He is generally smiling, speaks often (although not always coherently) and very much enjoys music and rhythm. He responds well to colors and pictures but is easily distracted by them, as well as by general noises. Neal has a thick blue play mat on the floor next to his bed, upon which all school sessions are conducted.

### **Medical History**

When I first met Neal, he was on a waiting list for a heart transplant and had already been hospitalized for several months. Born with Hypoplastic Left Heart Syndrome, Neal had recently endured a palliative procedure to redirect blood flow, has a gastrostomy tube and a PICC line in place and suffers from severe Epilepsy. Neal's medical records also indicate a significant developmental delay.

### **Questions For This Study**

Was Neal's developmental delay a result of his illness or his treatment? Or perhaps, not a result of either but further influenced by both?

After transplant, will Neal begin to gain a more typical level of functioning? Will his fine motor skills develop naturally with time?

### **Current Functioning**

Neal functions significantly below level in regards to nearly all aspects of his development. He is slow to warm up to anyone new that comes into his room, but after several visits, began to recognize me and would become excited about school

time. One challenge in working with Neal is that he tends to say “no” to nearly everything you introduce to him. However, when nudged is open to experimentation. He seems to prefer books that he can interact with and use his fingers and hands to touch. His favorite book is *Who Stole the Cookie From the Cookie Jar* and he not only likes but expects it to be read immediately upon a teacher entering his room. He can complete the endings to many of the sentences in the story with help from picture cues and/or by memory.

Neal needs to work on his fine-motor skills and on holding a writing utensil correctly. The best method is to do hand over hand with him and to use an oversized pencil or crayon. He holds the instrument in a tight fist and although I always place it in his right hand, which I believe to be dominant, he appears to want to use both hands (even though he has significantly less control over his left). He seems to enjoy most hands-on fine motor activities in which he is interacting with an adult but does not like to practice writing on his own.

### **Informal Assessment and Developmental Progress**

Neal is able to identify most beginning letters of the alphabet but seems to have more difficulty with lower case. He struggles with similarly looking letters such as “u” and “n”, as well as uppercase “I” and lowercase “l”. He needs to work on making the sounds of letters; he will often repeat after you if you say the letter and make its sound but has trouble coming up with it on his own. He will repeat new words if you ask him to. Neal seems to be able to identify low numbers, no higher than 10 and is able to count objects up to 10. He has a set of Thomas the Tank Engine flashcards in his room and likes to count and identify the numbers on the cards. We

have tried counting on a peg-board but the action of placing each individual peg seems to be too distracting for him. He enjoys puzzles but again becomes distracted by the pieces and appears to prefer either watching the puzzle being done or working hand over hand together.

Aside from the cookie book, Neal is beginning to sit for longer periods of time listening to other stories but becomes antsy and loses focus after a while. He appreciates patterns and repetition and likes to be read the same parts of stories over and over again.

After working with Neal for several months, I began to notice an improvement in his vocabulary and speech. Shortly after these developments began to take place, Neal got his new heart. After a successful surgery followed by several weeks in the ICU, Neal was back to work with the hospital school program. He had forgotten a great deal of what he learned, and there was obvious regression with regards to his motor and language skills. However, after some time he began to make progress once again. I believe that an intensive, multifaceted educational approach can and will continuously propel Neal forward and will enhance his learning potential and skill across developmental domains.

### **HEATHER, Age 10**

*“Protective Isolation- for patients whose immune systems have extra difficulty fighting off infection, wash hands, wear gown and gloves and mask, absolutely no sick contacts.”*

### **Background Information**

Heather is a quiet ten-year-old girl. She is thin, almost frail looking, and is of average height for her age. Heather lives with her parents and two younger siblings in a suburb a few hours from the city. She is enrolled in her local public school but hasn't been able to attend classes regularly for the past several months. She is very intelligent and her favorite subject is Science. Heather is very polite but shy and slow to warm up to strangers. She has a very close relationship with her mother, who is living nearby during Heather's hospitalization. Her father and younger brother and sister visit on the weekends.

Heather used to have long blond hair but has lost it all due to the treatment of her chronic illness. She has dark sunken eyes and her lips look as though they have lost their color. Although always pleasant and usually able to be persuaded by her mother, Heather is not always eager for school. Her social worker and Child Life specialist have asked us to try and push her, but there are many days in which she does not feel well enough to participate.

Heather is very intelligent and before becoming ill was an excellent student and enjoyed learning. Her favorite activity in the hospital is a circuit building science project, which I've seen her work with for hours at a time on her good days. However, more recently most visits with Heather simply involve my reading chapters of books to her. Even when she's not feeling well, listening to a story ideally provides some distraction and ultimately an escape from illness; stemming from the idea that reading gives us a place to go when we have to stay where we are.

### **Medical History**

Heather was hospitalized numerous times throughout the duration of my

internship for Acute Lymphocytic Leukemia, ‘without mention of having achieved remission’.

Bartel and Thurman (1992) describe cancer as “a disease in which one or more cells of the body divide more rapidly than is healthy. The most common childhood cancer, acute lymphocytic leukemia (ALL) is cancer of the blood-forming organs of the body, including the bone marrow, the spleen, and the lymph nodes... In this disease, the body produces a large number of immature white blood cells that are unable to develop into normally functioning parts of the immune system. These immature cells proliferate rapidly, crowding out and interfering with the manufacture of other crucial blood cells, including red cells and platelets,” (pg. 57). Heather’s treatment included several rounds of intense chemotherapy and radiation.

### **Questions and Concerns For This Study**

What are the benefits of School Services for a student who is so very ill?

Do these services make a difference in her development during hospitalization or are they simply an academic form of palliative care? Does it matter?

### **Summary of Reflections and Recommendations**

Shortly after the end of my internship, I learned that Heather passed away. When I had last been at the hospital she was in the ICU and I was told that her prognosis was poor. I suppose I knew it was coming, but it still came as a horrible shock. Heather was not the first patient I had worked with who passed away, but she was definitely the one I had spent the most time with. I can only hope that I made a difference in her life, at the least in her time in the hospital. I know she made a difference in mine.

### ***Program Summary***

Throughout my internship I have learned that the effective education of children with chronic illness depends hugely on a flexible, interdisciplinary approach that addresses their individual medical, psychosocial/emotional and academic needs. I have witnessed firsthand the necessity for normalcy in the pediatric hospital environment and the ways in which a hospital-based school service program can positively influence the development of children with chronic illness during periods of long-term hospitalization.

Results were seen in the forms of verbal feedback from family, nurses and social workers and the patients themselves. Parents consistently expressed gratitude and appreciation for school services and the message the services sent their children. It was generally agreed upon that participating in school services aided in the patients feeling less lonely, and more comfortable in the unfamiliar surroundings of the hospital. I was always amazed at the positive reactions I'd receive upon walking into a child's room and introducing myself. Just going into a patient's room and saying "I'm a teacher" provided an immediate connection to his or her regular life, outside of the hospital. In fact, many of the younger children would often respond "I have a teacher at my school!"

Throughout my internship, I worked with many students. Some I met only once. While others, like Jonah and Neal, I've spent countless hours with. On any given day, I might have interacted with as many as 30 patients and families and on top of my own students may have matched up and scheduled 4 or 5 tutors with kids eager for school services that day. Still, there never seemed to be enough time to see

everyone and do everything necessary. Although there were rare slow days every so often, it generally felt as though we just didn't have enough time or enough volunteers to meet the needs of all the patients that could benefit from educational services. Only it wasn't until I took a look at the statistics that I realized how many students we were simply unable to help.

During the first year of my internship, there were 178 school-aged patients admitted to the hospital on average each month. Of that 178, about 20 percent were eligible for the city's public hospital school service program. Whether they received those services is unknown. Regardless, 80 percent of students were not eligible for district services. Of that 80 percent, about 14 percent were considered to be 'inappropriate' for a variety of reasons. Of the remaining patients, 34 percent received appropriate services and 66 percent had academic needs that were unmet.

Could this be accurate? I crunched the numbers several times, with each matching result fueling my frustration. We were trying our best but there were simply not enough of us, not enough resources, not enough time, not enough program support. Shocked by the numbers, and not wanting to base my knowledge of the public school district program on unsubstantiated hearsay, I felt it necessary to gather documented information about the alternative to a hospital-based academic service program. At this point, it was only in my opinion and based loosely on observations, that the city's hospital school program in question may unfortunately resemble that of the district program Vivian Rankin (1993) last described as "disgraceful".

### ***The Public School System's Home/Hospital Program***

On my very first day as an intern, I walked into the teachers' offices to find an article placed on my desk. Just days before my arrival, there was a major cut in district and state wide funding, resulting in 226 Public School teachers left without jobs. In the July 2010 newspaper article, an Education reporter described the cuts, including those of many of the public school system's Home/Hospital teachers, as a "cash crunch that has spread like a cancer." I winced at the author's choice of words.

What this meant for the pediatric hospital in which I had just begun interning was that for the summer at least, the school service program would take on the cases of those students who would have otherwise received services from the local public school district. Come September, we'd have to wait and see. "What do you mean, wait and see?!" I asked my supervisor. Was it possible that these kids simply wouldn't be provided services at the start of the new school year? The answer, I learned over the next several months, was unfortunately yes, it's possible.

Ultimately, the Public School system pulled through and a few days into the 2010-2011 school year, a couple of veteran home/hospital teachers were back in the office. Throughout the year these teachers were in and out again, often unorganized and noticeably lacking support from their district. Further cuts took place and new faces appeared. The translucently flawed system begged questioning and necessitated research. Again, for the purposes of anonymity, the state and city in which this study took place will not be identified directly. The school services provided to children within the public school district will be addressed broadly as the city's Hospital School program.



The State Board of Education, Division of Funding and Disbursement Services (updated in November of 2011), explains that in regards to Home/Hospital Instruction the goal is “to afford the student experiences equivalent to those afforded to other students at the same grade level and are designed to enable the student to return to the classroom.” The district is required to provide services to any hospitalized child unable to attend school due to a medical condition. The student’s medical condition must be certified by a medical physician’s statement, indicating that the student will or is anticipated to be out of school for a minimum of 10 consecutive days or more or on an “ongoing intermittent basis.” An ongoing intermittent basis means that the student’s medical condition is of such a nature or severity that it is anticipated that the student will be absent from school for periods of at least 2 days at a time, multiple times during the school year, totaling at least 10 days of absences. Eligible children will regularly receive a minimum of one hour of instruction each school day, or in lieu thereof a minimum of 5 hours of instruction in each school week.

According to this particular state law, a teacher must be certified in Special Education in order to provide home/hospital services, regardless of whether or not her students are deemed to receive ‘special education’. In addition, a private/parochial school student may only be provided services by the district using Federal IDEA nonpublic proportionate share funds if he or she “has a disability” and is considered eligible for special education services.

Although I disagree with teachers needing to be certified in special education in order to work with students with chronic illnesses, these mandates seemed

reasonable enough. Only the issues we were seeing in the halls of the hospital, weren't really state issues, they were the problems and effects of the Public School system. Therefore, I thought it beneficial to take a closer look at the rules and regulations set by the city's current Home/Hospital instruction program.

Each year about 4,000 students participate in the Home and Hospital Instruction Program in this large Mid-western city. According to their Office of Special Education and Supports (OSES) Website, students who are hospitalized or too sick to attend school for ten (10) or more consecutive or intermittent school days are to be provided access to continuous instruction, by a certified teacher. Initial eligibility must be considered and documented by a licensed physician. The program claims to focus on keeping students in academic and instructional contact with their primary attendance school so that the reintegration is as seamless as possible.

While the program is not intended to duplicate or replace a full day of classroom instruction, ideally it does allow the student to maintain a sense of academic achievement and affiliation with his or her school. The homebound teacher and the classroom teacher are required to have ongoing conferences in order to achieve this goal. OSES regulations necessitate the homebound teacher to communicate with the classroom teacher on a weekly basis. In addition, the homebound teacher is expected to complete written progress reports to be submitted at the end of each marking period and at the end of hospital services. Students receive school attendance credit (1/2 day) for each instructional session.

On paper, this seems adequate. But it's just not what I saw taking place. I can't say whether it was a lack of support, or of effort, but it seemed clear that the

district's hospital school program was not putting its students first. (In fact, there were a handful of students whose parent's requested they be seen by the hospital-based program, instead). Not only did we take on those students, we also saw all public school Preschool and Kindergarteners as well. As Kindergarten is not required in the state, the public school system did not provide hospital services to anyone below first grade. Our hospital-based school service program might not be able to clock hours, or to administer national exams, but to the best of our ability we put the interests of each student first, and in a collaborated effort with medical staff, provided developmentally and situation-appropriate academic services to many deserving children.

## **Chapter V. DISCUSSION AND GENERAL CONCLUSIONS**

Once fully immersed in my internship and analysis of collected data, I began researching other hospital-based school service programs and noticed a staggering absence of them in the United States. In fact, I had trouble finding any. Curious about how other cities with large public school systems mandate and implement academic services to students with chronic illness during periods of long-term hospitalization, I looked first to my own hometown of Los Angeles, California for some answers. What I found was rather disconcerting.

### ***California Law and The Los Angeles Unified School District***

In the city of Los Angeles, there exist at this time no hospital-based school service programs. In other words, there are no programs that are A. funded by a pediatric hospital or its associated university and B. provide free and appropriate educational services to inpatient school-aged children. Therefore, a child who is not enrolled in the Los Angeles Unified School District (LAUSD) or whose family does not reside within the boundaries of the district, upon hospital admission has few options for receiving academic services.

Los Angeles Unified School District teachers are contracted into LA county pediatric hospitals through the Carlson Home/Hospital School, a division of LAUSD. Founded in 1946, the Carlson School provides services for eligible students who reside within district boundaries. Surprisingly, the program's website lacks any mention of school-aged students who reside within the district but do not attend its public schools, e.g., private or parochial school students. It does, however indicate

that the program is staffed by credentialed, contracted and retired teachers, and that services are “designed as temporary placements, not intended to replace regular required instructional programming but rather, to maintain continuity of the student's instructional program during the period of his or her convalescence”. (“Carlson Home/Hospital School”, 2011-2012). Services are also provided to students with an IEP or a Section 504 Plan.

In March of 2010, while visiting my family in Los Angeles, I was able to connect with an LAUSD teacher, working with the Carlson School and assigned to the UCLA Mattel Children’s Hospital. Throughout our meeting, the teacher (who requested to remain anonymous) explained that in order to be considered eligible for services, a student (in grades K-12) must have a medical referral from a licensed physician including a medical diagnosis. He or she must have a *noncontagious* condition or a temporary physical disability that will require an absence of ten or more school days. She noted that any student in isolation would automatically be denied services, regardless of whether or not that student was isolated for his or her own protection and was not considered to be contagious, or of any medical threat to others. I found this restriction to be particularly troubling, as evidenced in Chapter four, the majority of students with whom I worked during my internship were placed in some level of isolation for the durations of their hospital stays.

While the Carlson website claims that services are to be provided according to the availability of the student, there appear to be several heavily restricted issues of legality in alignment with the LAUSD guidelines and practices. For instance, students are entitled to only five hours of instruction per week. Secondary students are offered

instruction in two basic subject areas while Elementary students are offered instruction each week following an ‘Interim Elementary Course of Study’. Instruction must be arranged to take place between the hours of 8:00 a.m. and 4:00 p.m. on weekdays and will be given three to five times per week, as determined by the teacher and/or program administrator, (“Carlson Home/Hospital School”, 2011-2012).

The website does state that students eligible for services under Special Education, meaning they already have an IEP or section 504 plan in place prior to hospitalization, may receive services “as determined by their IEP or 504 Plan, if appropriate”. This means that if hospital services are not already written into the child’s IEP or 504 plan, the team must reconvene to determine if services are necessary and the document must be revised before instruction can begin.

The program’s website clearly states, as the Carlson teacher interviewed hesitated to confirm, “students with chronic diseases are generally not eligible for Carlson services,” (“Carlson Home/Hospital School”, 2011-2012). This startling fact can only result in a highly disproportionate number of hospitalized students in Los Angeles whose academic needs are simply unmet.

Children’s Hospital Los Angeles (CHLA) is Southern California’s first and largest pediatric hospital and has been affiliated with the Keck School of Medicine at USC since 1932. With its reputation and ample inpatient amenities and facilities, I was genuinely surprised to discover that they also do not provide school services to patients outside of LAUSD. Certainly worth mentioning however, is CHLA’s Literally Healing program. Perhaps the literacy-as-early-intervention-program most analogous with hospital schooling, Literally Healing supports the academic success

and lifts the spirits of inpatient students and their families through reading. The program consists of two components, the Therapeutic and Gifting libraries. According to the Literally Healing website, its Therapeutic Library includes over one thousand specially selected books, designed to help children “build mastery, courage and hope while they are in [the] hospital. Another component of the program uses books as gifts for patients to provide them with a source of distraction during their recovery.” Doctors, Social Workers and Child Life specialists can request specific recommendations for patients during particularly stressful times in their treatment and recovery. Professionals and trained volunteers then read these books to patients or encourage families to experience them together, often paving the way “for patients to disclose their worries and fears to their caregivers or their parents, fears that they might not otherwise have felt comfortable sharing.” The most common issues that are addressed through books include: living with serious illness, physical limits or disability, coping with negative feelings like worry, fear or sadness, dealing with siblings who are jealous of the attention the child is receiving, feelings of guilt for their condition, coping with changes in family structure, and dealing with the fear of death or feelings of grief.

Through generous donations the program also supplies inpatients with new, free books from its Gifting Library. The program believes that books can not only lift the spirits of patients but also provide an opportunity “to engage in an activity that they associate with life outside the hospital. Volunteers assist patients and families in selecting, delivering, and reading at the bedside. Each weekday that a child is an inpatient, he or she may select and keep one book, from board books for infants to

novels for young adults. Last year, the program donated over 30,000 new children's books to patients and their siblings.

### ***Massachusetts Law and The Boston Public School District***

After discovering how differently Home/Hospital programs are implemented and regulated across the country, I thought it might be beneficial to look into a third state system. Harvard Medical School's teaching hospital, Boston Children's is ranked best in the country. It was my thought that the very best pediatric hospital might just have the very best model for a school service program. So, I made some inquiries.

Upon visiting the hospital's website, I found several exemplary services for inpatient families, including the national literacy-as-early-intervention program, Reach Out and Read. This program was founded in 1989 by two Boston doctors and implemented at Boston Children's Primary Care Center in 1997. Similar to Los Angeles Children's Hospital's Literally Healing program, Reach Out and Read is designed to aid parents in their ability to promote early literacy skills and school readiness, its framework rooted in the belief that parents are a child's first and most important teachers.

The Reach Out and Read (ROR) model has three components: 1. At each check-up, between the ages of 6 months and 5 years, children receive a brand new, developmentally appropriate book from their primary care provider to take home. 2. Physicians and nurses are trained in literacy development to provide parents with guidance and support around the importance of reading to their children. 3.



Volunteers read aloud to children in the clinic waiting room and demonstrate appropriate reading techniques and modeling for parents.

While I was pleased to discover the Reach Out and Read program, and believe strongly in its guiding principles, I unfortunately wasn't able to uncover any other academic programs offered directly to students who are inpatient for extended periods of time. Without finding a hospital-based school service program, my next step was to contact the Boston Public School's Human Resources department to find out about their Home/Hospital program. I somehow managed to finagle a name and an email address, and figured it was worth a shot. However I never expected to reach an actual human being, much less connect with someone so willing to help.

Luck, it seems, was again on my side when I received a phone call from Kevin DeForge, (K. DeForge, Personal Communication, November 16, 2011), licensed social worker and the director of Home and Hospital Instruction for Boston Public Schools, a division of the Massachusetts Department of Education. Mr. DeForge took a generous amount of time to speak with me about the services his program provides. During our conversation I learned that Massachusetts law allows a school district to determine how its hospital services are to be delivered. While this concept was certainly not a new one, I was very surprised to discover that the Boston Public School system's hospital school services, including those provided to patients at Boston Children's, are contracted out to private education agencies.

According to DeForge (November 16, 2011), through these agencies instruction is provided on an individualized schedule. The school district determines the number of instructional hours per day or per week based on the educational and

medical needs of the individual student. Unlike in Chicago and Los Angeles, school districts in Massachusetts may not preset the number of instructional hours per week provided to in the hospital. Services are to be determined in the best interests of the student and in consideration of the medical circumstances of the student.

According to the Massachusetts Department of Education's Program Quality Assurance Services Website, ("Program Quality Assurance Services", 2005) in regards to the Implementation of Educational Services in the Home or Hospital, the overall intent is "to provide a student receiving a publicly funded education with the opportunity to make educational progress even when a physician determines that the student is physically unable to attend school." The program acknowledges that "while it is impossible to replicate the total school experience through the provision of home/hospital instruction" a school district must provide the instruction necessary to enable the student to keep up in his/her courses and to minimize the educational loss that might occur during the period of hospitalization.

Although the regulation on home/hospital instruction is included in Massachusetts' Special Education Regulations, home/hospital instruction is not considered "special education". That is, unless the student has previously been found eligible for special education. In other words, home/hospital instruction typically is considered a regular education service. While Special Education services are also provided, there are separate regulations included relating specifically to students who are likely to be confined to home or hospital for medical reasons for more than 60 school days in any school year. The Massachusetts regulation (603 C.M.R 28.03(3)(c)) requiring educational services in the home or hospital reads as follows:

Upon receipt of a physician's written order verifying that any student enrolled in a public school or placed by the public school in a private setting must remain at home or in a hospital on a day or overnight basis, or any combination of both, for medical reasons and for a period of not less than fourteen school days in any school year, the principal shall arrange for provision of educational services in the home or hospital. Such services shall be provided with sufficient frequency to allow the student to continue his or her educational program, as long as such services do not interfere with the medical needs of the student. The principal shall coordinate such services with the Administrator for Special Education for eligible students. Such educational services shall not be considered special education unless the student has been determined eligible for such services, and the services include services on the student's IEP.

Under Massachusetts law, there are separate regulations for public school and private school students. A public school student is enrolled in a public school district or a charter school, or is being educated with public funds in an educational collaborative or an approved private day or residential special education school. If this student, due to documented medical reasons, is confined to home or a hospital for more than fourteen (14) school days during the school year, he or she is entitled to receive home/hospital educational services. This requirement for a school district to provide home/hospital instruction to a public school student is *not* dependent upon the student's eligibility for special education. However, this is not the case for those enrolled in a private school (at private expense). He or she is entitled to receive

publicly-funded home/hospital instruction as a special education service only if he or she has been found to be a student with a disability who requires special education.

Massachusetts Law (G.L. Chapter 71B, § 1) defines "school age child with a disability" as follows:

A school age child in a public or non-public school setting who, because of a disability consisting of a developmental delay or any intellectual, sensory, neurological, emotional, communication, physical, specific learning or health impairment or combination thereof, is unable to progress effectively in regular education and requires special education services, including a school age child who requires only a related service or related services if said service or services are required to ensure access of the child with a disability to the general education curriculum.

If the private school student already has an IEP under which the school district is providing special education services, then during the 14+ school days that the physician says the student will be out of school for medical reasons, the school district must provide the specially designed instruction and/or related services described on the student's current IEP, modified as necessary to accommodate the student's medical needs.

If the private school student does not have an IEP and will be out of school for medical reasons, s/he may be eligible for special education services if the student's medical condition is determined to be a health impairment that adversely affects the student's educational performance. Under these circumstances, the parent is entitled, at any time, to request and receive an evaluation of the student by the public school

district to determine if the student's medical condition meets special education eligibility requirements.

A private school student who has been determined to be a "school age child with a disability" is entitled to receive publicly-funded special education services in accordance with an IEP developed by the school district of residence. The school district may not refuse to evaluate the student because s/he is enrolled in private school or because s/he is currently out of school for medical reasons.

If the private school student does not have an IEP and the parent does not wish to refer the student for a special education evaluation, the parent may contact the school district of residence, providing documentation from the student's physician that the student is confined to home or hospital for medical reasons for not less than 14 school days during the school year. The school district may, at its discretion, provide home/hospital instruction to the student, using the district's resources to provide the instruction, but it is not required to do so unless the student is evaluated and found to be eligible for special education.

Hospital Education Services can be accessed once a student's personal physician determines that a medical condition will require him or her to be out of school for not less than 14 school days. The physician must then notify the school district responsible for the student and must provide the student's principal or appropriate program administrator with information regarding the date the student was admitted to a hospital, the medical reason(s) for the confinement, the expected duration, and any medical needs to be considered in planning the hospital education services.

Students with chronic illnesses who have recurring hospital stays of less than 14 consecutive school days, but are expected to be out of school for a total number adding up to more than 14 school days in a school year, are also eligible for home or hospital educational services, if they are requested and the medical need is documented by the physician.

Hospital educational services are to begin as soon as the school district receives written notice from the student's physician, as there is no required waiting period. In fact, whenever a student is likely to miss 14 school days or more for health-related reasons, the Department of Education “strongly recommends that the school district expedite the delivery of educational services as well as any evaluation or Team meetings that may be necessary, in order to minimize the negative impact on the student's educational progress”. (“Program Quality Assurance Services”, 2005)

After learning of the restrictions in California, the most important question I asked Mr. DeForge was whether students with chronic illness were always eligible for special education services. He explained that it depends on the individual case. According to Massachusetts law, any student with a medical or health condition that is likely to lead to an extended school absence or “inability to maintain effective educational progress is a reasonable candidate to be referred to the public school district” to determine special education eligibility:

If assessment information indicates that the student's educational progress will be adversely affected as a result of a chronic or acute medical condition that is not temporary in nature, then the Team will likely determine that the student is eligible for special education. An eligibility determination is an individualized

decision that depends on the facts of each case. In most cases, if the Team determines the student is eligible, the type of disability as recognized by federal and state special education law will be a "health impairment" (see 603 CMR 28.02(7)(i)). In some cases, the assessments may indicate other types of disability, such as "emotional impairment" or "neurological impairment. ("Program Quality Assurance Services", 2005)

If the student has been evaluated and found eligible for special education, the Team will write an IEP describing the special education and related services that the student needs and the school district will provide. If the student will be out of school for medical reasons for an extended period of time, it is appropriate to include on the IEP educational tutoring as a related service that the student needs in order to access the general curriculum while he or she is in the home or hospital setting. The IEP may be tailored to address expected time periods when the student is unable to attend school, if that is deemed appropriate to meet the unique needs of the individual student.

### ***Summary***

After reviewing each of these programs, it seems that the provision of a successful hospital school system would ultimately entail professional teachers trained both in school and hospital environments, helping to bridge the potential communication gap and maintain contact with the primary school during a child's treatment period. Referrals for services need to be made in a timely manner, rather than delaying action until the student is absent for significant periods of time or has begun to experience educational failure. In regards to the return back to school,

schools should receive support from staff knowledgeable in best practices, documented instructional strategies and recent research relative to the needs of all students. Regardless, health care and educational systems must work together to better provide these services.

When comparing state systems, it seems perhaps that the Massachusetts policies might be most beneficial to students. However, there remain the problems with funding and the questions: has the issue of accountability become financially driven? Is that a problem? Does it matter? Might there be an even deeper and more sensitive issue here?

While the answer to this last question beckons further in-depth research, it's important to think about. It is generally agreed upon that hospital school services are hard to track, require a special staff and an incredible amount of flexibility, and are of course expensive. However, a review of these programs also highlights the ways in which each system takes care of its most vulnerable members and in turn, speaks to the integrity of those systems. By reducing or removing options for chronically ill children, administrators are also indicating a disregard for their educational needs and overall well-being. It is certainly ugly, but could it also be seen as discriminatory?

### ***Conclusions***

The purpose of this study was to broaden the existing knowledge of the effects of educational services on development, thereby increasing the health-related quality of life, in children with chronic illness during periods of long-term hospitalization. In an attempt to satisfy its purpose, this study examined the collision of Education and



Healthcare in the pediatric hospital environment and questioned whether today's educational policies and delivery systems adequately address the active epidemiology of child health care in the United States. The exploration of this question derived from an examination of factors within several school systems and hospital programs that attempt to promote an effective provision of services.

The aims of this project were to first identify successful strategies and models of good practice, as well as to identify those that appear to be failing. Secondly, to develop a set of standards including multi- and inter-disciplinary collaboration, joint provision and training initiatives, flexibility and proper acknowledgement of diverse and individual student needs, staff development, and policy documentation and dissemination. And finally, to encourage a more deliberate action involving recommendations for improvement in communication, outreach, and advocacy efforts and to counteract current and emerging threats to the educational services provided to this too-often-forgotten population of children.

The findings from this study provide theoretical, research-based and clinical implications for treatment and intervention efforts for school-aged children with chronic illness. It has become apparent through this research that there is a strong need for a re-evaluation of the laws and acts that protect the educational rights of these children, specifically in regards to the concept 'special education'.

There is also a great need for further development and implementation of hospital-based and funded school service programs to ensure that all students with unique medical needs receive appropriate educational services. In order to support equal access to educational opportunities for children whose health condition impacts

their learning experience, “an important consideration related to studying childhood chronic illnesses is the definition and criteria used to identify children with. Future researchers and practitioners need to establish a more commonly accepted definition and criteria for ‘childhood chronic illnesses’ so that varying criteria are not used across multiple research studies,” (Martinez and Ercikan, 2008, p. 399).

It is necessary to raise awareness of the educational challenges associated with chronic childhood illness; especially at a time “when inclusion has become a key element of the government’s policy on education, it seems that this complicated issue has been left on the periphery. A plethora of literature exists on the negative impact that exclusion from education has on life opportunities. However, this does not seem to have included exclusion that occurs as a result of children becoming ill,” (Harris and Farrell, 2004, p. 14). The results of this study suggest a more deliberate crossover of educational and medical social policy research, including specialized legislation and standards for educators and healthcare professionals working with this population of students.

### ***Limitations***

Elliot Eisner’s benchmark resource, *The Enlightened Eye: Qualitative Inquiry and The Enhancement of Educational Practice*, provides its readers with a promising understanding of qualitative educational research and evaluation. In the book, Eisner (1991) asks the multifarious question “how do you know that you know?” His question beckons an examination of the validity of qualitative research, acknowledging that “there are some who believe that what is personal, literary, and at

times even poetic cannot be a valid source of knowledge,” (p. 107). He counters however that using multiple layers of data can provide “a confluence of evidence that breeds credibility, that allows us to feel confident about our observations, interpretations, and conclusions,” (p. 110).

In regards to this particular study, whose multiple layers of data consist of observations and journal recordings, casual interactions, and perhaps even firsthand experience, Eisner’s words help to define its foreseeable limitations. These include the risks of generalization and researcher bias. In regards to generalization, this study is not intended to serve as a representative sample of hospital schools in general, but of the observations of one researcher’s experience at one pediatric hospital. It is also important to keep in mind that the fluid and often-unplanned nature of the pediatric hospital population poses unintentional obstruction to a more stable subject sample.

In *Enlightened Eye*, Eisner (1991) also writes about the epistemology of insider-ness, which he refers to as “connoisseurship.” He notes the importance of understanding that throughout his text, his use of the term ‘knowledge’ must include an awareness of its intricacies:

We need not make a statement or claim to know what is before us. And during the course of most of our lives we do not. We not only know more than we can tell, as Polanyi (1967) has said, we tell far less than we know. Our knowing does not depend on our telling. Our telling is a way of making public what we have come to know. Connoisseurship is the means through which we come to know the complexities, nuances, and subtleties of aspect of the world in which we have a special interest, (p. 68).

In regards to my own researcher bias, I have inevitably formed personal connections with many students and families throughout my internship. Although I am aware that the idea of researcher bias often carries with it a negative connotation, for the purposes of this project, I believe these connections have truly enhanced my work. In addition, my own recent diagnosis and treatment has allowed for a deeper and more personal perspective. Perhaps, it has also provided more thorough credibility with regards to the implications of my research findings, as well as my future practice. I believe my inescapable researcher bias to most certainly stem from my own insider knowledge, my personal connoisseurship.

### ***Redefining Care***

About a month ago, I was perusing the New York Times online *Health and Wellness* section. This activity had recently become a favorite procrastination method, as I could argue that it technically still pertained to my writing. Therefore while surfing the web, I was in fact still ‘working’, not reading about how to make Spring Rolls From Fall Vegetables. I glanced down at the table in front of me- stacks of highlighted med-psych journal articles, a pile of scribbled notes I’d taken during interdisciplinary rounds, my now very worn copy of Anne Fadiman’s novel, *The Spirit Catches You and You Fall Down*- I glanced back up and scrolled down the page, suddenly my stomach flipped. On my screen was an article written by Margalit Fox, Published: September 14, 2012. *Lia Lee Dies; Life Went On Around Her, Redefining Care.*

Fox's article reads like sparknotes-turned-obituary. It begins with the explanation that the novel's title, 'The Spirit Catches You and You Fall Down' is the English translation of the condition known as *qaug dab peg*, the Hmong term for epilepsy, which Lia Lee had suffered from since infancy. She lived the last twenty-six of her thirty years in a 'persistent vegetative state'.

Fox argues that Lia's story "has had a significant effect on the ways in which American medicine is practiced across cultures, and on the training of doctors." In fact, the book is often assigned in medical schools, "at the Yale School of Medicine, for instance, the incoming class is required to read it — a tradition that was begun a dozen years ago, well before Ms. Fadiman herself began teaching at Yale".

Lia Lee died of pneumonia on Aug. 31, 2012, but her story remains far-reaching: "A lot of people in medicine were talking about that book for a very long time after it was published," explained Sherwin B. Nuland, the physician and award-winning author in Fox's article. He added, "There's a big difference between what we call 'disease' and what we call 'illness.' A disease is a pathological entity; an illness is the effect of the disease on the patient's entire way of life."

Arthur Kleinman, a psychiatrist, medical anthropologist, and chair of the department of social medicine at Harvard Medical School believes "every illness is not a set of pathologies but a personal story," (Fadiman, 1997, p. 262); preferring not to review a patient's 'case' but rather her 'narrative'.

This paper makes some pretty strong claims, with rather unrelenting and understandably difficult demands. Its intention is absolutely to provoke, to rouse the reader into taking action, to challenge lawmakers and educators and hospital

administrators to take better care in providing educational services to these children. But really, this paper is just a collection of stories. My story. Jonah's story. Lia's story. They are all narratives, woven together to create a case for more considerate education.

In *Spirit*, perhaps the most compelling argument is communicated over plates of fish at the Red Snapper Seafood Grotto in Merced, CA, the town in which Fadiman's book takes place. In a heated discussion over cross-cultural pediatrics, and Lia's case in particular, two characters disagree on which takes priority: the life or the soul. The doctor argues, "you have to act on behalf of the most vulnerable person in the situation... and that's the child," (Fadiman, 1997, p. 277). Next to the repeatedly underlined and highlighted sentence, I had scribbled in what is now just faded pencil, during my first of many readings- *that's what a teacher does*. Now, more than ever, I know this to be true.

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