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# BRIDGING THE GAP BETWEEN HOSPITAL AND SCHOOL: ADDRESSING THE ACADEMIC AND SOCIAL-EMOTIONAL NEEDS OF STUDENTS WITH CHRONIC ILLNESS

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Education in the College of Community Innovation and Education at the University of Central Florida

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### **ABSTRACT**

This dissertation in practice examined the literature and a sample of existing programs that addressed the educational and social-emotional challenges of students with chronic illness in order to bridge the gap between hospital discharge and school re-entry. Literature showed that the hospital homebound setting was problematic for chronically ill students due to minimal hours of academic instruction and little interaction with peers. Students with chronic illness were at higher risk for maladaptive behaviors, lower educational attainment, and higher use of social services. Programs created at other facilities to address this problem were visited and reviewed for pertinent information such as funding sources, location, division of responsibility, and relationships with school districts. Those findings were incorporated into a hospital-based learning center model designed to address both the academic and social-emotional needs of elementary students using the Positive Youth Development (PYD) framework.

The design process included a focus group of hospital professionals (music therapy, child life, and family-centered care), school district partners (literacy), university partners (art), and parents of chronically ill students. The focus group reviewed the model and provided feedback on the design based on their expertise and modifications were made by the researcher to the design. Webex-Teams, an online meeting platform, was used for stakeholders to review modifications to the physical layout and analyze a proposed sample interdisciplinary session plan. The final model design included five components: literacy, art, music therapy, play, and technology, a physical floorplan, and an interdisciplinary session plan to address the academic and social well-being of chronically ill students that can be replicated at any hospital facility.

For my	daughter	Sarah,
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I'm sorry for all the missed ball games, nights of homework, crazy weekends away, and stolen moments when my mind was focused on this. I might have come up short in the mothering department at times, but I hope when you look back on this, you'll remember that I persevered and finished what I started because of you.

## **ACKNOWLEDGMENTS**

The completion of this dissertation was quite a (long) journey and I am incredibly grateful to those who helped this (weary) traveler along the way.

To my committee members, Dr. Spalding and Dr. Taylor, I am grateful for your input and expertise. Dr. Vitale – You have been with me from the beginning and I'm glad to have had your humor and perspective. Dr. Hopp - Thank you for the gentle nudges along the way, for holding me accountable, and always expecting the best despite my circumstances. Your guidance and wisdom made this dissertation better, and in turn, made me better.

To my stakeholder focus group: I am forever grateful for your participation and I can't wait to see where this project leads. Thank you for your compassion and enthusiasm to make this project relatable, replicable, and unique.

To my family: To Matthias - Thanks for holding down the fort so I could get this done. Sarah – I owe you a vacation or two. Lukas - This model was designed for you and for other kids like you. You inspire me to be better and do better. Mom –Thanks for watching the kids so I could work and for letting me camp out at your place for weekends at a time. No matter how old I get, I still need my Mom and I'm glad you are here to see this finally completed.

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# LIST OF ACRONYMS AND ABBREVIATIONS

ACE Adverse Childhood Experience

AdPT Adlerian Play Therapy

ATR-BC Board Certified Art Therapist

CCLS Certified Child Life Specialist

CREATE The Center for Research and Education in Arts, Technology, and Entertainment

EST Ecological Systems Theory

H-BLC Hospital-Based Learning Center

IEP Individual Educational Plan

LRE Least Restrictive Environment

MT-BC Music Therapist – Board Certified

OCPS Orange County Public Schools

PYD Positive Youth Development

RPT Registered Play Therapist

### **CHAPTER ONE: INTRODUCTION**

## **Problem of Practice**

Dissertations in Practice are designed to identify a problem of practice and seek solutions that are supported by research and literature related to the identified problem. Solutions to problems of practice can be in the form of a new program, a model design, or program evaluation. The solution also includes a theoretical or conceptual framework that will support the rationale for the selected solution to the problem of practice. The anticipated outcome of the presented solution is that it will be beneficial to the education profession, and in this case, children with chronic illness.

Students with chronic medical issues are often placed in a hospital homebound program which can unfavorably impact their academic and social development (Madan-Swain, Katz, & LaGory, 2004). Academically, hospital homebound students' educational progress is hindered by inadequate instructional time, teacher preparedness, and logistical issues that affect access to special education services (Bessell, 2001). If this interruption occurs during the elementary school grades, it negatively impacts literacy skill development which affects future reading, writing, speaking and listening abilities. The limited number of instructional hours per week places increased educational demands on the parents of the homebound student (Rehm & Rohr, 2002). Further, students with chronic medical issues are less likely to graduate high school, attend college, and have a lower level of job attainment and increased use of social services (Maslow, Haydon, McRee, & Halpern, 2012). The hospital homebound setting allows for minimal face-to-face peer interaction. This lack of social interaction can lead to isolation, withdrawal, and difficulty reintegrating back into school (Madan-Swain et al., 2004). Students

also may encounter slower social maturation and are at a higher risk of anxiety and depression. Extended absences can lead to skill regression and a decrease in social function (Maslow et al., 2012).

Because placement in a hospital homebound setting can adversely impact student's social and academic development, the problem of practice this dissertation in practice will address is the absence of social and academic opportunities provided by the hospital homebound setting.

# **Exploratory Questions**

There are two exploratory questions that were addressed by this dissertation in practice:

- 1. What essential skills support literacy development in elementary students with chronic illness during an extended absence from school, prior to their return to school?
- 2. What therapeutic interactions support the social-emotional well-being of elementary students with chronic illness during the time they are unable to attend school?

#### Context

Shaw and McCabe (2007) postulate that one of the reasons students need academic assistance between the time they leave the hospital and return to school is that the healthcare system, and treatment of chronic illnesses, have evolved to the point where patients are being discharged from the hospital much earlier than in the past. This early release from the hospital allows students to heal at home but can lead to additional absenteeism from school. Additionally, more time to convalesce at home places more educational responsibility on parents. These parents face an increased need for respite care as they address the stress that chronic illness can bring to a family (Rehm & Rohr, 2002).

Students hospitalized or receiving treatment for a chronic illness miss valuable instructional time due to their health issues. The average number of absences during an academic year for a healthy student is just over three academic days (McDougall et al., 2004). The average annual number of absences of a student with chronic illness are variable - students with cystic fibrosis miss an average of 19 days and asthma may lead to absences between 12-36 days (Shaw & McCabe, 2007). In addition, the percentage of students with chronic health conditions refusing to attend school is five times greater than their healthy peers (Shiu, 2001). This school phobia can be attributed to separation anxiety and can be manifested as physical pain in some children. Parents sometimes compound this problem by allowing their children to stay home which further increases the separation anxiety (Sexson & Madan-Swain, 1993).

#### Hospital Homebound Placement

Hospital Homebound is one of the special educational placements determined by the creation of an Individualized Education Plan (IEP). To initiate entry into a hospital homebound program, the parents of a child with a chronic illness complete an application that permits the school (or district personnel) to contact the child's doctor. Occasionally, if there is a planned absence, due to a surgery or known hospitalization, the process of placing a student on hospital homebound can begin prior to excessive absenteeism. However, the student is more likely placed in this program retroactively, which leads to additional missed schooling. Once contact between the school and doctor is initiated, the doctor justifies the student's need for hospital homebound services and then returns the documentation. Once medical approval has been given, the school

district meets with the family to determine the number of hours per week of instruction the student will receive.

For an elementary school student, this number ranges from one to five hours of instruction per week. Middle school students can be eligible for more hours depending on their course load. The school then locates a teacher willing to instruct that number of hours at the student's home – the preference of local school districts is to locate a teacher that is known to the child (Seminole County School District Representative, personal communication, February 14, 2018). In the case of an elementary hospital homebound student, this instructor may be their classroom teacher or a teacher who previously instructed the student. Once the teacher is identified, there can be up to an additional ten-day delay before services start due to processing requirements. The length of time it takes for students to begin to receive hospital homebound services can be considerable, ranging from ten days to seven weeks. This delay has further implications on both the social and academic well-being of the student. According to Seminole County Public Schools, one main source of the delay was the slow communication of medical needs from the physician to the school district (Seminole County Public Schools representative, personal communication, February 14, 2018).

Although 'hospital' is included in the title of this educational placement, very rarely does instruction take place within the hospital. One district hospital homebound representative stated that hospital time should be focused on healing (Seminole County Public Schools representative, personal communication, February 14, 2018). When pressed about the education of children who have long hospital stays, she stated that would be addressed on a case by case basis, but again reiterated that hospital time was for healing, not for education.

Traditionally, the location of hospital homebound instruction is a multifaceted problem with both geographical and political implications. These include district policies that prohibit crossing county lines for hospital homebound instruction and an overall lack of inter-district cooperation. Additionally, hospital homebound policies also preclude student participation in community events, work, or extra-curricular activities which further limits interaction between chronically ill students and their peers. (Seminole County Public Schools, 2019).

## **Population**

Current estimates suggest that chronic health issues impact more than 10 million schoolaged children in the United States (Elias, Murphy, & Council on Children with Disabilities, 2012). Shaw and McCabe (2007) approximate that chronic illness affects 18% of school-aged children. Of those, 6.5 % have illnesses severe enough to interfere with normal school activities, and 1.5 % are impacted to the extent that alternative educational placements, such as Hospital Homebound are necessary- see Figure 1.

Orange County Public Schools' K-12 enrollment was 209,144 students in 2018. Florida's 2018 total K-12 public school enrollment was 2,846,857 (Florida Department of Education, 2019). In the most recent data published by the National Center for Educational Statistics (2019), the total United States K-12 public school enrollment was 56.6 million in 2018. If we applied the percentages from Shaw and McCabe (2007) to the most recent enrollment numbers, 3,137 Orange County Public School students would need alternative placements such as hospital homebound.

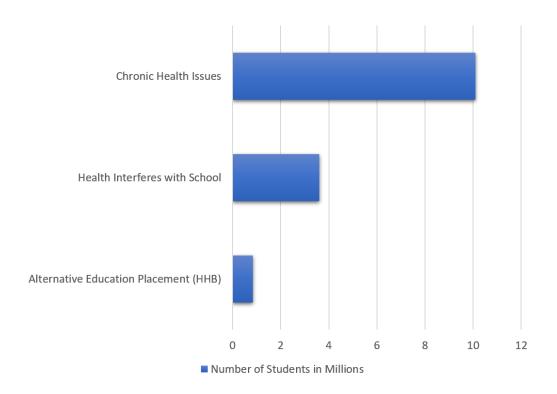


Figure 1: Chronically III Students in the United States Shaw and McCabe (2007), National Center for Educational Statistics (2019)

Chronic illness is a local, state, and national problem that may impact as many as 37,600 students in Orange County Public Schools, 512,400 students in Florida, and 10.2 million students in the total United States school population. While difficult to quantify international numbers, the literature base on this topic includes research in countries such as Sweden, Germany, Belgium, and Japan. It is possible to infer that other developed countries suffer from similar challenges in educating this population of students.

# Significance of the Problem

## **Academic Implications**

Hospital homebound services are billed as a temporary solution for medical needs and are not designed to replace a traditional academic experience or to completely replace instruction in the classroom (Seminole County Public Schools, 2019). However, the number of hours of instruction are well below that received in a typical classroom. Elementary students can be eligible for just one hour of instruction per week. Often students are given packets of homework to complete without the associated and necessary instruction. Missed instruction can lead to educational gaps in learning, particularly in elementary students. The skills learned in the early grades are the foundations for future academic concepts. Missing these skills and concepts can obstruct future learning.

Academic motivation in elementary school is a great predictor of motivation in future grades (Gottfried, Fleming, & Gottfried, 2001). Medical issues and frequent absences can lead to additional impacts on academic motivation and persistence, as well as interrupt the continuity of academic concepts which can impede academic progress. Students who display academic competence on school tasks have increased levels of motivation in the early elementary grades and that motivation can lead to higher academic achievement (Luster, Lekskul, & Oh, 2004). With deficits in competence and motivation, future academic progress can be impacted.

Students with chronic health issues can also suffer from educational impairments due to their illnesses, or from the treatment prescribed for their condition. Treatments that impact a student's central nervous system (for example - medications for seizures, chemotherapy, and radiation) can initiate or exacerbate learning difficulties. Students with diabetes can lose valuable

learning time due to hypoglycemia, a decreased level of blood sugar (Clay, 2004). Frequent breathing treatments for students with cystic fibrosis, not only interrupt the learning process but side effects of those treatments can lead to anxiety or focus issues. When a child is in pain from an illness, the pain can cause a reduction in their ability to focus and complete educational tasks.

Compared to their healthy peers, students with chronic illnesses are at a greater risk of encountering educational, vocational, and financial problems (Maslow et al., 2012). They are less likely to graduate from high school or attend college and graduation rates for students with chronic illness are less than half of their healthy peers (Maslow et al., 2012). These factors influence students with chronic illnesses and their ability to make academic progress while facing their health issues.

#### **Social-Emotional Implications**

"School attendance for the child who has developed a chronic health problem may be as critical for social survival as medical treatment is for the physical survival" (Sexson & Madan-Swain, 1995, p. 361). There are also social-emotional implications for students with chronic illnesses. Students with chronic illnesses are at a greater risk for social isolation, withdrawal, difficulty reintegrating back into school, and have a higher risk of anxiety and depression. (Kaffenberger, 2006; Madan-Swain et al., 2004; Maslow et al., 2012). Frequent absences remove students from their peers and may lead to poorer peer relationships. These absences disrupt friendship formation and can lead to a lack of social support which then can make students increasingly susceptible to additional life stressors (Shiu, 2001).

Chronically ill children encounter additional stressors from internalizing the anxiety and stress of their parents and siblings. Parents of chronically ill children also may attempt to shelter the chronically ill student for fear of bullying or teasing because of their condition and therefore become overprotective (Rehm & Bradley, 2006). While well intentioned, this overprotectiveness further removes chronically ill students from their learning communities and friendships, reducing their availability to receive the support they need (Clay, 2004). Challenges faced by chronically ill students are compounded by navigating the complex academic hospital homebound placement which can also increase the amount of stress placed on an already taxed family unit (Mescon & Honig, 1995). Exposure to such stressors elicits both a behavioral and physiological response. Figure 2 details three types of stress response. Sustained stresses, such as those encountered from a chronic illness, can lead to a toxic stress response.

POSITIVE	TOLERABLE	TOXIC
Physiological response to mild or moderate stressor	Adaptive response to time-limited stressor	Maladaptive response to intense and sustained stressor
Brief activation of stress response elevates heart rate, plood pressure, and normonal levels	Time-limited activation of stress response results in short-term systemic changes	Prolonged activation of stress response in children disrupts brain architecture and increases risk of health disorders
Homeostasis recovers quickly through body's natural coping mechanisms	Homeostasis recovers through buffering effect of caring adult or other interventions	Prolonged allostasis establishes a chronic stress response
Tough test at school, playoff game	Immigration, natural disaster	Abuse, neglect, household dysfunction

Figure 2: Continuum of Stress Responses

Reprinted with permission from *Toxic Stress in Children and Adolescents*, Bucci, Marques, Oh & Harris, 2016, retrieved from <a href="https://doi.org/10.1016/j.yapd.2016.04.002">https://doi.org/10.1016/j.yapd.2016.04.002</a>, Copyright 2016 by Elsevier Inc.

The concept of toxic stress is usually included in the discussion of Adverse Childhood Experiences. Adverse Childhood Experiences (ACE) include childhood household dysfunction, abuse - physical, emotional and sexual; neglect, and other exposure to childhood trauma. The more ACE exposure, the higher the likelihood of long term health and psychological issues (Burke Harris, Silvério Marques, Oh, Bucci, & Cloutier, 2017). The financial and emotional impact coupled with additional stressors that a child with a chronic illness can bring to a family, can lead to household dysfunction. This dysfunction constitutes chronic illness as an Adverse Childhood Experience.

Toxic stress occurs when an individual experiences frequent and prolonged exposure to adversity without the buffer of protective factors such as a sense of belonging or supportive relationships. This exposure, if it transpires during particular times in the developmental process, changes a child's physiological response to stress. Eventually this dysregulated stress response can lead to changes in brain function and increases the risk of health and behavioral disorders in the future (Bucci, Marques, Oh, & Harris, 2016). Additional research from the American Academy of Pediatrics (Shonkoff et al., 2012) examined the longitudinal effects of toxic stress on the development of children. This research shows that early childhood toxic stress can lead to future maladjusted behaviors such as increased use of drugs and alcohol, higher risk for poverty, and lower educational attainment. As these toxic stress exposed children become parents, they are less likely to provide the stability to protect their own children from the impact of toxic stress (Shonkoff et al., 2012).

Students with chronic illness would benefit from programs geared toward reducing the duration and impact of toxic stress (Burke Harris et al., 2017), increasing protective factors -

including a sense of belonging and supportive relationships (Maslow et al., 2012), and reducing social isolation (Kaffenberger, 2006). Addressing this issue while these chronically ill students are young could contribute to a reduction of expensive community resources in the future (Shonkoff et al., 2012).

### **Organizational Context**

This problem involves two key organizational types: a children's hospital, which treats children with chronic illnesses, and a local school district. As this dissertation in practice addresses the gap between hospital discharge and the return to school, the hospital will serve as the main organization. AdventHealth was founded in Orlando, Florida in 1908 and began with the purchase of a farmhouse used as a tuberculosis treatment center by the Seventh Day Adventist Church. From those beginnings, the AdventHealth System was established and has grown to include ten hospitals in the central Florida area. AdventHealth for Children is a non-profit children's hospital that is owned and operated by the AdventHealth System. This hospital is one of the three dedicated pediatric hospitals in the greater Orlando, Florida area. The hospital opened in 2006 and currently has a patient capacity of 198 beds with an annual inpatient caseload of 4,642 patients, AdventHealth for Children employs 828 employees, and has 259 physicians (AdventHealth Orlando Media Resources, 2019).

The mission of AdventHealth is to "extend the healing ministry of Christ" and the hospital is deeply entrenched in the teachings of the Seventh Day Adventist faith. As an expansion of that faith-based mission, AdventHealth developed a philosophy of how to achieve a

well-balanced and healthy outlook based on biblical principles. This model, called CREATION Health, is detailed in Figure 3.



Figure 3: CREATION Health Philosophy (Creation Health, 2015)

In 2011, a partnership with the Walt Disney Company culminated in the opening of the Walt Disney Pavilion at AdventHealth for Children. This partnership, the first of its kind, paired the interactivity of Disney in a healthcare setting. Each of the seven floors were designed to integrate a Disney theme and an interactive, jungle themed lobby was built.

AdventHealth for Children is a mission-focused organization. They rely heavily on their CREATION Health model to guide their initiatives. The partnership with Disney encourages

innovative and child-friendly solutions. This organization is uniquely poised to address the academic and social-emotional issues of this student population. As a non-profit organization, they also contribute significantly to regional initiatives and a portion of their revenue is earmarked for community-based improvements.

AdventHealth for Children resides in Orange County, Florida. Orange County has a population of 1.38 million total residents and covers 903.4 square miles. (U.S. Census Bureau, 2018). Orange County Public Schools (OCPS) is the school district that services all of Orange County. OCPS is the ninth largest school district in the United States with a 2018 enrollment of 209,144 students (Florida Department of Education, 2019). OCPS has 258 schools, and employs 12,480 teachers (National Center for Educational Statistics, 2018).

# **Positionality**

Positionality requires the researcher to examine their role in the research process and their relationship with participants. Herr and Anderson (2015) theorize that understanding your role as an outsider or insider within the context of the research will allow for a greater understanding of how the participatory research can affect change. My role in this context is multi-faceted. I am the parent of a child with multiple disabilities with several Individualized Education Plan (IEP) designations. He also has a chronic, terminal illness and has utilized hospital homebound services in the past. He spends an average of 120 days per year in the hospital missing valuable academic instructional time. Through the process of obtaining hospital homebound educational services for him, I discovered that our local school district did not have well established parameters to address the needs of hospital homebound students. Not only were

the academic services very limited, there was a great delay in access to necessary resources. This experience did not seem unique to my child.

In addition to my role as a parent, I am also an educator advocating for solutions to address issues faced by this student population. Since 2012, I have explored the idea of designing a model of outpatient experiences for home-bound, chronically ill students prior to their return to school that could provide supplemental academic and social opportunities. I am a member of the Family Advisory Council at AdventHealth for Children and tasked with examining hospital policies and procedures to improve the pediatric patient experience at the hospital. Herr and Anderson (2015) describe action research as research done by or with organization insiders to examine organizational programs, problems, and outcomes. An insider in this context, is one who has intimate knowledge of the hospital homebound placement as well as the inner workings of the services and interventions of the children's hospital. My positionality would be that of an "insider in collaboration with other insiders" (Herr & Anderson, 2015, p. 40). This positionality will allow me to collaboratively work with other insiders (those who work with, or support, chronically ill students) to affect change and potentially develop this program model for AdventHealth beyond the hypothetical.

#### History and Conceptualization

Educating students with chronic illnesses is a fairly recent problem brought on by advancements in medical treatment (Shaw & McCabe, 2007). In the educational system prior to the Civil War, students with illnesses did not attend school. If they were lucky to endure their illness, they rarely had access to a formal education. The development of special schools for

chronically ill children began after the Civil War, but those students were segregated and no accommodations were made for their unique academic and social needs (Clay, 2004).

Educational reform in the early 1900's required all students, regardless of illness or disability to attend school. However, chronically ill students were often segregated (especially at the height of polio and tuberculosis outbreaks) and received limited, if any, assistance in accessing academic curriculum (Clay, 2004). In the early 1970's, during the civil rights movement, important legislation passed that greatly impacted the schooling of students with disabilities - including students with chronic illnesses (Clay, 2004). The Rehabilitation Act of 1973 guaranteed access, equal opportunities, and governmental services. This act allowed for legal recourse if discrimination occurs. The most important section of this act is Section 504 which states:

No otherwise qualified handicapped individual.... shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

-United States Department of Labor (n.d.).

A document called a 504 Plan developed from this section of the legislation. A 504 Plan allows students with chronic illnesses to receive a few accommodations without formally placing the student in a special education program (Zirkel, 2009).

The Education for All Handicapped Children Act of 1975 (also known as Public Law 94-142) addressed many issues that faced students with illnesses or disabilities. It included a provision to develop an Individualized Education plan (IEP) which addresses the specific needs

of each student. This legislation also mandated services that gave students greater access to the school environment. These included curriculum modifications, medication administration, therapies (physical, speech, and occupational), transportation provisions, and supplemental tutoring. This law also provided a path of legal recourse should the rights of the student be violated. Public Law 94-142 encompassed students age 6 through 17 but the age range was expanded in 1980 to include students age 3 to 22. This age adjustment, particularly to include the years prior to kindergarten, signaled a shift in focus on early intervention. If a student was determined to be qualified for services, they were placed into various categories based on their disabilities, see Table 1. Students with chronic illnesses often fall into the Other Health Impaired category.

Table 1: Individual Education Plan Categories

<u> </u>	
Autism Spectrum Disorder	Multiple disabilities
Deaf-blindness	Orthopedic impairment
Deafness	Other health impairment
Developmental delay	Specific learning disability
Emotional disturbance	Speech or language impairment
Hearing impairment	Traumatic brain injury
Intellectual disability	Visual impairment, including blindness

The original legislation passed in 1975 was subsequently expanded, revised, and renamed the Individuals with Disabilities Education Act (IDEA, Public Law 101-476). This expansion included transitional services from school age to adulthood and assistive technology. IDEA was evaluated in the early 1990's and reauthorized with new amendments in June of 1997. It was these amendments that included and strengthened the requirement that students be educated in the least restrictive environment (Taylor, 2004).

Placement in a general education setting is not appropriate for every student. Therefore, the Least Restrictive Environment (LRE) is determined based on the services the student requires. Figure 4 shows the LRE placement continuum from least restrictive to most restrictive. Ideally, a least restrictive environment would provide the most interaction with their non-disabled peers, supplementary special educational services (i.e. speech, language, and physical therapy), intensive instruction, and access to extracurricular activities. Hospital homebound placement is considered the most restrictive placement due to the lack of peer interaction, access to special education services, and the minimal academic instruction provided (Taylor, 2004).

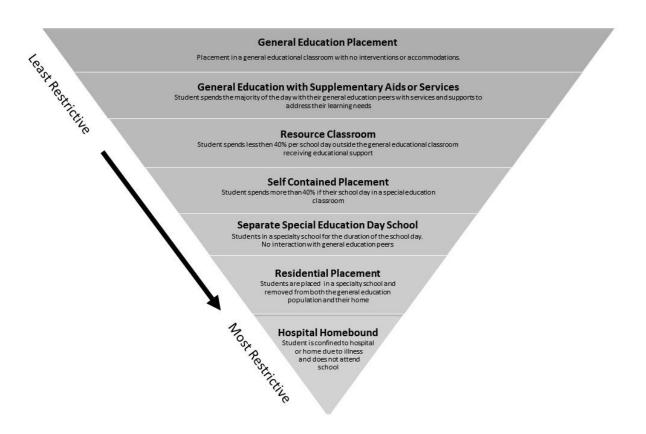


Figure 4: The Least Restrictive Environment Placement Continuum Adapted from (Edison Township Public Schools, n.d.)

# **Prior Solutions**

# Video - Conferencing

One way that schools and homebound students have been able to connect is through video conferencing utilizing programs such as Skype, a type of Voice Over Internet Protocol (VoIP) that allows users to communicate via voice and video to participate in face-to-face interactions. Macharaschwili and Coggin (2013) utilized a model of blended learning they entitled a "Skype-Buddy" model. This model paired a virtual student and an in-class participant together during several lectures at a university level using Skype. Although this program was geared toward an older population; the model could be applied to younger students.

Simeonsdotter Svensson, Pramling Samuelsson, Hellström, and Jenholt Nolbris (2014) conducted a study that examined the use of Skype with Swedish preschoolers. Their study found that there were benefits to using this modality, such as the fact that a preschooler was able to attend a class session from their own home. An additional positive outcome was that parents were able to attend virtually with their child, assisting their child with staying on task and participating to the fullest extent. In our chronically ill student scenario, additional responsibilities such as these could add additional stress on an already stressed family (Mescon & Honig, 1995).

The challenges of utilizing a modality such as Skype or Facetime, a similar Apple product, is that the camera and microphone are in a fixed location and one must move the entire device (laptop, tablet, or phone) to participate, which can potentially lead to challenges while working with larger groups. Additionally, internet service interruptions and issues with the Skype program prevented full participation in some members of the Swedish study

(Simeonsdotter Svensson et al., 2014). As an alternative, Beeman and Henderson (2012) discuss using a dynamic video conferencing system that allows for additional interactivity. This video system includes the ability to pan and zoom around the classroom which would allow the student to have a dynamic interaction with the class. This video system, the VGo System, is exponentially more expensive than utilizing other static VoIP programs.

#### **Robots**

Building upon the video conferencing solution, a relatively newer solution to address both the academic and social needs of hospital homebound students is using interactive educational robots. These robots, such as the one in Figure 5, utilize interactive video conferencing tools with the addition of mobility. The agility of the robot allows the robot to travel between locations and allows for social interaction during non-academic school time.



Figure 5: Robot Example - Double Robotics (Double Robotics, 2019)

Robots are currently being used across the United States for this purpose. A company called Double Robotics, sells their base model for \$3000, which makes it cost prohibitive for most school districts as each hospital homebound student would require their own robot. There have been instances where the community has crowd-sourced (via social media funding) the cost of the robot to allow the student to attend school virtually (Double Robotics, 2019).

The literature base to evaluate the effectiveness of using this novel robotic solution is minimal. While much of what has been published are mainstream media articles or white papers from corporations selling the products, there is a published study by Newhart, Warschauer, and Sender (2016) that found that this form of virtual inclusion allowed students to not only access the academic opportunities provided by attending school, but also provided a way to address the social-emotional needs of chronically ill students. Classmates of the student using the robot accepted the technology replacement quickly after a period of transition. There were instances of verbal abuse, some physical altercations, and some bullying toward the homebound student using the robot, but the overall experience was positive for both the school and the homebound student (Newhart et al., 2016). For the intended population of students examined by this dissertation in practice, students in grades kindergarten through fifth grade, this solution poses both logistical and operational concerns. While this option might be easy for technologically savvy older students, younger students might need additional assistance in maneuvering the robot, which would then place higher involvement and additional workload on families.

### Virtual Schools

Virtual school models are a way to meet the educational needs of a chronically ill student, although this form of education requires extensive parental support (Allday, 2012). It can be utilized by hospital homebound elementary students; however, it only minimally addresses the social/emotional well-being of these students. The virtual school model keeps the same attendance data as a traditional school, so frequent hospitalizations and illnesses might prevent students from staying on track with their courses. The freedom to take courses from home is a benefit for this modality, the emphasis on parental involvement and attendance requirements might exclude many students with chronic illnesses.

# **Hospital Schools**

There are several hospital school programs throughout the United States that have been implemented with varying degrees of success. One of the largest, and most well-known hospital schools is located at Lucile Packard Children's Hospital in Palo Alto, California. This inpatient program was established in 1924 and is a collaboration between the Children's Hospital at Stanford University and the Palo Alto Unified School District. There is also a similar inpatient program at the University of Nebraska Medical Center with a small outpatient component.

Most of the hospital school programs are staffed and funded by local school districts.

These programs provide a roving teacher to meet with students who are unable to come to the hospital classroom and a few limited hours of multiage educational settings per day. They provide minimal educational support once the child is discharged from the hospital and none of

the hospital school programs examined have no known available interventions to address the students' social and emotional needs.

### Factors that Impact the Problem

These prior solutions have addressed some of the academic and social needs of this student population, but none of these solutions effectively mitigate both the inadequacy of the limited amount of instruction received during hospital homebound or the impact on the social and emotional health of these students. I conducted a review of the literature surrounding the education of students with chronic illness in order to examine this problem in more detail. The longitudinal outcomes of students with chronic illness are similar to those exposed to other types of household dysfunction (Shonkoff et al., 2012) but can be mitigated by protective buffers such as a sense of belonging and caring adults (Burke Harris et al., 2017). In terms of schooling options for children with chronic illness, the hospital homebound setting was also found to be the least preferred academic setting (Searle, Askins, & Bleyer, 2003).

Age is also a factor that impacts the problem. This dissertation in practice will focus on students in elementary school (kindergarten through fifth grade) as other proposed or past solutions are geared toward older students. It is particularly important to connect younger chronically ill students because unlike their older classmates, younger students do not have well-established social networks and are less likely to have social media connections to their peers.

The most likely cause of this problem exists in the framework of the hospital homebound placement itself and the delay in receiving homebound services. Not only is hospital homebound

placement the most restrictive placement, it removes students from their peers and provides inadequate amounts of academic instruction.

### Model Design

This Dissertation in Practice will present a design of an outpatient Hospital-Based

Learning Center (H-BLC) that will serve students, kindergarten through fifth grade, who have
chronic illnesses that require them to be absent from school more than fifteen days during the
academic year. The H-BLC design is intended to mitigate both the academic and socialemotional disruptions that result from an extended school absence. This H-BLC would be
centrally located in the greater metropolitan Orlando area at one of the three main children's
hospitals, AdventHealth for Children. Initially, the school would include students from Orange
County Public School District with the option to incorporate other regional school districts in the
future.

The purpose of the design for this Dissertation in Practice was to develop an outpatient program model to bridge the gap between the hospital and school re-entry that addressed students' social and literacy development. To achieve this, the program model approached the needs of chronically ill students utilizing the Positive Youth Development (PYD) framework. Examples of existing PYD programs include Boy Scouts, Girl Scouts of America, 4-H, and the Boys and Girls Club of America. This framework, developed from Bronfenbrenner's (2005) Bioecological Systems Theory, included five components (Five C's); Competence, Confidence, Connection, Character, and Caring. Table 2 defined each of these components (Lerner et al., 2005). The design consciously addresses all five of these components through literacy and social

programming. Maslow, Hill, and Pollock (2016) found the holistic PYD perspective addressed both the academic and social needs of this student population and worked to mitigate the impact of toxic stress.

Table 2: Components of Positive Youth Development

Five C's	Definition
Competence	Positive view of one's social, academic,
	cognitive and vocational actions.
Confidence	Positive self-worth and self-efficacy.
Connection	Positive bonds with people and institutions.
Character	Respect for societal and cultural rules.
Caring	Empathy and sympathy for others.

Adapted from (Lerner et al., 2005).

Literacy skills are critical skills for elementary school students, and a multi-age, multi-level focus on literacy will continue to develop and support these skills. The literacy activities are standards-based, developmentally appropriate activities that address essential literacy skills focused on reading, writing, listening, and speaking. For example, a literacy activity might be a story read to the group with the directive to focus on listening for key details. The students would then use those details to put story panels in the correct order as a way of reinforcing that concept. Another proposed session would include a dynamic storyteller who focuses on listening and speaking as she involves the students in the creation of the story. There is also an arts integration component included with the literacy activities. Hetland and Winner (2001) found that integrating the arts into literacy instruction led to novel skill development, specifically in verbal abilities, which then transferred to new literacy experiences. The literacy and arts focused interventions address all five components of the PYD framework.

To address the social and emotional needs of these students, opportunities for socialization with other students in similar situations will help promote a sense of belonging and reduce the sense of isolation. These opportunities include music therapy, play, and targeted literacy and art experiences. The therapeutic interventions allow students to gain a better understanding of the challenges they face and how to channel those difficulties into creative expression and develop peer relationships. The social-emotional interventions address all five elements of the PYD framework and are guided by Certified Child Life Specialists and Certified Music Therapists using play and musical therapy activities.

In addition to the literacy and social support, the physical layout is conducive to engaging students from a wide spectrum of physical and medical needs. Most hospitals have specific directives and standards that physical environments must adhere to. Therefore, designing the structure of the physical environment was not a focus of this project, but the physical design helped facilitate the conversation about programmatic elements to be included in the H-BLC. It was suggested that the H-BLC be wheelchair accessible, have ample lighting, accommodate medical equipment, and have the same contact and cleanliness procedures as a hospital.

### Stakeholders

Data show that students with chronic illnesses face a multitude of both health and social problems as they age (Bucci et al., 2016). Therefore, there were many stakeholders in this design process. The stakeholders in this model design were students with chronic illnesses, their families, hospital homebound teachers, district administrators, hospital administrators, child life

specialists, music therapists, play therapists, and community agencies. Many of the stakeholders were invited to participate in the focus group.

### Model Development

To acquire necessary information to properly develop this plan, I examined two existing types of hospital school programs, specifically those at Lucile Packard Children's Hospital and the University of Nebraska Medical Center. These programs were reviewed to glean pertinent information such as funding sources, location, division of responsibility, accountability, and relationships with school districts to incorporate those findings into the project model. Lucile Packard Children's Hospital was selected for inclusion as it is the oldest hospital school program in the United States and for its long-standing partnership with a local school district. The examination of Lucile Packard Children's Hospital program was conducted through websites, email correspondence, and telephone interviews. The University of Nebraska Medical Center's hospital school program was selected because it represented a different type of program funded by the hospital and had a minor outpatient component. Information acquired from the University of Nebraska Medical Center's program was obtained by the researcher's personal experience through inpatient care, visiting the school, and additional email correspondence. While there is no literature base for the efficacy of hospital schools, examining these two programs in closer detail assisted in the decision-making process for the model.

# Focus Group

Once background information on these two existing hospital school models was completed, a preliminary model design was developed. A focus group that included representation from AdventHealth for Children, Music Therapy, Child Life, a local school district, parents of chronically ill students, and university partners convened to review the proposed model design. After gathering data and incorporating the ideas and expertise generated by the focus group, the model design underwent revisions. This revised design was presented virtually to the same group at two distinct intervals for feedback - once after the completion of the redesign of the physical layout, and once at the completion of a proposed session plan. The feedback data acquired from the virtual sessions was then incorporated into the final model design.

#### Documentation

The process was documented through a series of different iterations of the hospital-based learning center model design. The design process was also documented cumulatively with the changes and justification for those changes clearly detailed on each iteration of the model design. The focus group's virtual feedback (utilizing a virtual meeting space program), were clearly identified and documented at two key stages: during the review of the physical space, and during the review of a proposed session. The intended product was a usable model that could be implemented by any hospital to address the social and academic needs of hospital homebound students.

# **Summary**

Chapter One provided a detailed explanation of the complex problem of practice that was addressed by this dissertation in practice. The organizational and historical contexts of the problem were provided. An overview of prior solutions for this problem and their outcomes were described as well as a plan to obtain and analyze data to develop the program model. The subsequent chapter will discuss the proposed model components.

### **CHAPTER TWO: PROPOSED DESIGN**

### **Problem of Practice**

The hospital homebound placement limits the number of hours of instruction and opportunities for peer interaction. The possible deficits that result can have long lasting academic and social-emotional impact as children with chronic illness are at a heightened risk for behavioral and emotional problems (Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007).

Academically, a child may fall further behind due to the inadequate hours of instruction provided by the hospital homebound setting. After an illness, students may struggle socially and may have feelings of isolation, withdrawal, and encounter difficulties reintegrating back into their school.

#### Goals and Outcomes

The goal of this project was to design a model of a Hospital-Based Learning Center (H-BLC) that addressed the gap in services from the time a student is discharged from the hospital until they are cleared to return to school. The H-BLC program was designed to provide supplemental opportunities to continue to develop literacy skills, while addressing the social-emotional issues unique to students with chronic illness. Participation with peers in activities involving art, music therapy, and play allow students to develop a sense of belonging, growth, understanding, and independence that will assist them in the reintegration back to school.

#### Similar Contexts

The University of Nebraska Medical Center in Omaha, Nebraska has a hospital school program. As this hospital conducts a large amount of pediatric multi-organ transplants, there are

several transplant patients that have extended hospital stays necessitating educational intervention. There is one Nebraska certified teacher at the hospital whose salary is funded through the hospital instead of the local school district. This program started approximately 30 years ago and it serves an average of five students daily through both one-on-one sessions and whole group learning experiences that are collaboratively programmed with the Child Life Department. This school does have its own school room in the hospital, but it can only accommodate two students at one time. Many of the one-on-one tutoring sessions happen in the common area. Although this school collaborates more with the Child Life department, there are very few therapeutic play activities included in these learning sessions. These collaborative sessions are available for students that are not in the hospital, but social-emotional assistance is minimal and informal (Lisa Gulseth, personal communication, December 11, 2017).

The Lucile Packard Children's Hospital School program grew out of a collaboration with the Palo Alto Unified School District and was established in 1924. This program allows students to experience familiar school routines in an unfamiliar hospital environment. All teachers are California certified teachers; two at the elementary level, two at the middle school level, and three at the high school level and their salaries are funded through the school district. There is a designated school location and posted school hours (Monday – Thursday the hours are 9:30-11:30am and 1-3pm, and Friday 9:30-11:30am). If a student were to attend all available hours, they would receive 18 hours of instruction per week. This far exceeds the amount provided by local hospital homebound placements. For students that are unable to attend school in the classroom, bedside instruction is provided. This school also provides drama, art, and science as enrichment – but none of the supplemental services are designated therapeutic interventions

(Stanford Children's Health, 2019). This program services both inpatient and outpatient students but is strictly academically focused and does not address the social-emotional issues faced by this population.

AdventHealth for Children is situated in the middle of Orange County Public Schools, the ninth largest school district in the United States (National Center for Educational Statistics, 2018) and many patients come from the surrounding thirteen central Florida counties.

Developing partnerships with each of these surrounding counties would be possible, but challenging, and significantly delay the implementation of this model and delay students from obtaining the assistance that they need. Establishing this program as a school would require the H-BLC to meet established standards to earn and keep accreditation and require reciprocal arrangements with all the surrounding school districts. For these reasons, the H-BLC is supplementary to hospital homebound services and will not seek to establish a school setting. The naming of the H-BLC as a "learning center" was intentional to make that distinction.

#### Theoretical Foundations

**Ecological Systems Theory** 

The predominant theory that this program model was based on is Bronfenbrenner's (1979, 2005) Ecological Systems Theory (EST) - the idea that development is a product of the interaction of a person and their environment. "The ecology of human development involves the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts

within which the settings are embedded" (Bronfenbrenner, 1979, p. 21). Bronfenbrenner (1979) examined the interactions within and between the four systems -microsystem, mesosystem, exosystem, and macrosystem within the context of the individual to provide elements of understanding of the developmental process. Since these systems are nested within each other, changes to one system can impact the other systems (Neal & Neal, 2013).

### Positive Youth Development

Out of Bronfenbrenner's work grew programs focused on positive youth development. This model approached development from the perspective that all children have positive qualities that can be developed and this approach moved away from a deficit view of focusing on preventing negative behaviors (Geldhof et al., 2014). Positive Youth Development (PYD) programs focus on opportunities to develop certain positive behaviors in the microsystem and mesosystems by creating a conducive environment for growth and development. PYD is used in many well-known settings such as the Boy Scouts, Girl Scouts of America, 4-H, and the Boys and Girls Club of America.

According to Lerner (2004), there are three essential characteristics of effective PYD programs. These "Big Three" characteristics are sustained positive relationships between a child and caring adult, life skills acquisition, and opportunities for leadership and service. Integrating these "Big Three" into a PYD program can lead students to stronger outcomes in the five main PYD developmental elements - character, confidence, competence, connection, and caring (Sendak, Schilstra, Tye, Brotkin, & Maslow, 2018). Children that have greater development in these areas will have fewer maladaptive behaviors and will be able to contribute more to their

communities (Maslow et al., 2016). Maslow (2012; 2016) found that participation in a PYD program for children with chronic illnesses resulted in similar positive outcomes as their healthy peers. Activities in the H-BLC were intentionally structured to include the "Big Three" and address the five components of PYD.

## Key Elements of Design

There are four key elements to this design that address both the academic and socialemotional needs of this student population while incorporating the five components of Positive
Youth Development. These four elements were chosen because they have been shown to benefit
the academic and social-emotional needs of chronically ill students, several of these elements are
already in existence at the hospital, and partnerships between AdventHealth for Children and
community partners would reduce the financial impact of this program's development. The HBLC design, and subsequent activities, are to supplement a student's existing hospital
homebound instruction. This program utilizes four different modalities; literacy engagement
activities, art instruction and integration, music therapy, and play.

#### Literacy Engagement

When examining the academic needs of students with chronic illness, it was clear that replacing the student-specific hospital homebound instruction was not feasible. The content covered for each student was both grade specific and standards-based and it would be a challenge to meet the individualized academic needs of each student in the allotted time without the support of a full-time educator and assistance from the school districts. In order to augment the instruction provided by hospital homebound services, literacy became a focus for this

program because language arts skills are necessary life skills that will benefit children regardless of their grade or ability level. These skills will be based on Florida Standards and will focus on reading, speaking, listening, and writing. Although the population for the center is kindergarten through fifth grade, the design includes the fifth grade Florida Standards as the "goal" standards for this program (Appendix B). The goal is that all students will be working toward mastering the standards to exit fifth grade regardless of grade level. Working toward a standardized goal will also allow some continuity of educational outcomes between the H-BLC and their home school.

These literacy experiences need to be adapted to the mental and physical capabilities of every child in the H-BLC. All materials should be accessible to non-readers and non-writers and projects adapted to meet those with fine motor deficits by consulting with the hospital occupational therapy team. By including literacy activities in the H-BLC, students will have shared experiences with their peers, continue to engage in speaking, listening, writing, and reading tasks that will impact their future literacy skills, and to interact with others. Participation in literacy activities with their peers will provide students the opportunity to develop a sense of belonging while sharpening key communication skills important for social-emotional development.

One of the advantages to using the H-BLC as a supplemental program is that these literacy activities do not need to be conducted by a Florida certified teacher. The planning of such activities, as well as the differentiated nature of the experience, would need to be conducted by someone who has familiarity with the fifth grade Florida Standards for English Language Arts to ensure that opportunities for listening, speaking, reading and writing are included. The

presentation of the literacy component (story, activity, etc.) could be accomplished by any member of the community which will allow for special guest readers and stakeholders to actively participate in the H-BLC.

### Example of Literacy Activity

The Color Monster by Anna Llenas (2012) would be read to a small group of kindergarten through second grade students. This book seeks to untangle a monster's jumbled emotions, identify them and how they feel, and put them in jars so that they can be easily identified and addressed. Students will then receive a monster puppet to color their emotions using the color scheme from the story and provide an oral explanation of their color choices. This activity addresses Language Arts Florida Standard, LAFS.5.RL.1.1 which states: Quote accurately from a text when explaining what the text says explicitly and when drawing inferences from the text (CPALMS Florida State University, 2019).

#### **Arts/Arts Integration**

AdventHealth for Children had a certified art therapist on staff who worked with inpatient children on art projects. They no longer have a dedicated art therapist and are relying on volunteers from the community to integrate art into their inpatient programming. Without a consistent volunteer base, it was necessary to locate an organization willing to assist with the integration of arts into this program model. The Center for Research and Education in Arts, Technology, and Entertainment (CREATE) is a program in the College of Arts and Humanities at the University of Central Florida, a large, metropolitan university in central Florida. CREATE partners with many community agencies, schools, and several Positive Youth Development

programs (Boys and Girls Club) and conducts multidisciplinary projects with those agencies.

These projects include summer camps, educational research, and focus on Science, Technology,

Engineering, Art, and Mathematics (STEAM) activities.

CREATE, the university partner, developed mobile art kits to be used in a hospital setting. The art kits are self-contained boxes, like a fishing tacklebox, containing several basic art items such as scissors, glue, markers, watercolor pencils, colored pencils, and other assorted art supplies. The art kits can be utilized in both a group and individual setting but are made to be used by one individual so that there is no scarcity of supplies or cross-contamination with medically fragile students. The art lessons can be integrated within the literacy lesson, or as a separate activity, which is a strength of the design of the art kits and adding CREATE as a dynamic university partner will be mutually beneficial to all parties.

Participation in art and art therapy has been shown to increase assertion, cooperation, communication, and problem solving skills, and decrease hyperactivity and off-task behaviors (D'Amico & Lalonde, 2017). Coholic and Eys (2015) found that participating in an arts-based mindfulness activity improved confidence, social skills, and self-esteem. Morris and Willis-Rauch (2014) found an increase in social empowerment by allowing students control over what art they created and how they displayed their results. This population of students so rarely get to control any aspect of their lives or medical care, so autonomy and independence are valuable.

The planning of the art/arts integration activity would need to be conducted by someone with an arts background – particularly skilled with using art as a therapeutic medium. A Board Certified Art Therapist (ATR-BC) requires a master's degree and an 100 hour supervised practicum and a 600 hour internship and passing the Art Therapy Credentials Board Examination

(American Art Therapy Association, 2017). A Board Certified Art Therapist or an Art Therapy intern acquiring clinical hours would be ideal to achieve the highest level of therapeutic benefit, but if one is unavailable, a person with suitable art instruction expertise and passion will be sufficient. This modality also lends itself to having members of the community and stakeholders as guest artists.

### Example of Art Integration Activity

CREATE's Lead STEAM instructor provided a suggested art activity (Chealsea Anagnoson, personal communication, January 24, 2019). In this activity, students read a poem by Shel Silverstein and then draw an illustration to accompany the poem. After the completion of the illustration, the students compare and contrast their drawing with the illustration from the author. This arts integration activity utilizes a literacy experience, reading a poem, as a foundation for an art project.

### Music Therapy

Music Therapy is the evidence-based and clinical use of music and musical interventions to address the social, emotional, neurological, physical and spiritual well-being goals of an individual (American Music Therapy Association, 2019). AdventHealth for Children has a well-developed Music Therapy program. Music therapy can take place in many settings – both inpatient and outpatient. In this program model, there would be opportunities for small group music therapy and individualized sessions. Music therapy for children has been shown to be "particularly effective in improving mood and affect regulation, communication, social skills, and quality of life" (Stegemann, Geretsegger, Phan Quoc, Riedl, & Smetana, 2019, p. 9). In the

H-BLC setting, music therapy goals might include increasing a sense of belonging, decreasing isolation, and providing a sense of autonomy.

To become a Music Therapist – Board Certified (MT-BC), it is necessary to complete one of the more than 70 existing academic preparation programs in the United States leading to a degree in Music Therapy (American Music Therapy Association, 2019). Candidates must then complete 1200 hours of clinical field training and pass the Certification Board for Music Therapists (CBMT) Exam before they are considered a certified music therapist (The Certification Board for Music Therapists, 2011).

## Example of Music Therapy Activity

Two eight-year-old boys met for a small group for a session of music therapy while they were in the hospital. Just before the program started, they were discussing their "evil" twin who often misbehaved and led to them getting in trouble with their parents. Instead of conducting the previously planned session, the music therapist and boys sang children's songs in a minor key (to make them sound evil) while spontaneously rewriting lyrics. They developed songs such as "Twinkle, Twinkle Evil Star" and "If You're Evil and You Know It, Give a Roar!" This shared experience and interaction gave the boys a sense of connection and belonging.

#### Play

Play is instrumental for the developing child. It provides ways to communicate, promotes intellectual and social-emotional aspects of development, and "play is the predominate context in which children interface with their environment" (Koller, 2008, p. 55). Child Life Specialists focus on assisting children in managing emotions, expectations, and medical anxiety through

play (American Academy of Pediatrics, 2014). Not only is play developmentally accessible, Child Life Specialists use medical play to reduce anxiety as well as to identify and provide coping mechanisms. This type of play has been shown to reduce physiological responses such as sweating, tachycardia (rapid heartbeat) and hypertension (increased blood pressure) (Koller, 2008). These physiological signs are similar to those with toxic stress exposure – where children with chronic illnesses can have a heightened and almost constant state of anxiety. Over time, toxic stress can cause maladaptive behaviors. (Shonkoff et al., 2012) and play has been shown to ameliorate some of these symptoms.

AdventHealth for Children has a well-established Child Life program. The inclusion of play in the H-BLC will also give students continuity of care in which they can continue to develop their relationships with trusted hospital personnel in an outpatient setting. Focusing on the importance of play in the H-BLC will allow students additional interactions with their peers. Free play has several benefits as well, and as these children are mostly isolated from others, even the opportunity to play a game with another child is a welcome respite. By having play facilitated by a child life specialist, the conversation and depth of understanding can be increased with some guided probing questions.

The title of Certified Child Life Specialist (CCLS) is awarded by the Association of Child Life Professionals. To apply to be a CCLS, a bachelor's degree in any field and the completion of courses from either an accredited Child Life Studies program or approved coursework is required. The internship component is 600 hours and candidates must achieve a passing score on the certification exam (Association of Child Life Professionals, 2018).

### Example of Play Activity

In order to prepare children for a magnetic resonance imaging (MRI) procedure, AdventHealth for Children developed a program called "Picture Perfect." In this Child Life led program, the child comes to the imaging center prior to their MRI and hears the MRI machine sound, practices laying down in a model MRI machine, and participates in medical play with a doll placing the doll in the MRI machine. The instruction given is developmentally appropriate and catered to each child and is intended to alleviate any anxiety leading up to the MRI scan (AdventHealth for Children, n.d.).

### Play Therapy

Child Life Specialists are not licensed mental health providers and when a student has mental health needs that exceed the scope of the Child Life Specialist's position at the H-BLC, they will be referred to a Registered Play Therapist. Play Therapy is a therapeutic use of play to address mental health issues by providing a developmentally appropriate medium, play, for children to express their emotions (Association for Play Therapy, 2018, May 24b). Play Therapy would be reserved for those children who, for example, show signs of suicidal thoughts or other major behavioral symptoms that would need to be addressed by a licensed mental health professional.

One type of play therapy approach is Adlerian Play Therapy (AdPT). AdPT approaches behavioral issues by reframing them in positive terms, which then allows the child to acquire a different perception of the world (Russell, Oh, & Dillman Taylor, 2019). To achieve this, a Play Therapist moves through the four phases of Adlerian therapy which can be found in Table 3.

This approach will only be conducted by a Registered Play Therapist.

Table 3: Phases of Adlerian Play Therapy

Phase	Goal	Phase Details
Phase 1	Relationship Building	This phase of AdPT focus on developing a relationship with the child with an equal share of power between the child and therapist.
Phase 2	Investigating	This phase examines the child's life using a variety of constructs. This information is gathered from observations and input from other adults and used to develop a treatment plan.
Phase 3	Gaining Insight	This phase helps the child obtain a greater awareness of patterns of behaving, thinking, and feeling and how these patterns affect other aspects of their life. Also addressed is if, and how, the child wants to make changes to those patterns.
Phase 4	Reorienting	This phase provides the child new ways to redirect their changed thoughts and feelings with opportunities to practice these different patterns of behavior in a variety of settings.

Adapted from (Meany-Walen & Kottman, 2019).

Lin and Bratton (2015) found that play therapy "demonstrated the greatest benefit for broad-spectrum behavioral problems, children's self-esteem, and caregiver—child relationship stress" (Lin & Bratton, 2015, p. 54). The inclusion of Play Therapy would distinguish the H-BLC and AdventHealth for Children as one of the few nationwide hospitals that utilize play therapy in a clinical setting (Russell et al., 2019). Including the use of Adlerian Play Therapy conducted by a Registered Play Therapist in the H-BLC addresses the mental health challenges faced by students with chronic illness.

A Registered Play Therapist (RPT) is certified by the Association for Play Therapy (Association for Play Therapy, 2018, May 24a). This certification requires a minimum of a master's degree in mental health and state licensure, a two-year, 2000-hour clinical experience,

150 hours of play therapy instruction, and 500 direct play therapy clinical hours.

## Physical Design

A cursory physical space was designed, mostly to facilitate the focus group discussion about what elements to include in the H-BLC, can be found in Figure 6. Each of the four main components have their own space and location in the room. A small office was created to allow for individual play therapy sessions, as recommended by Russell et al. (2019). A parent area was also added with viewing of the entire program through one-way glass. As this student population suffers from many different complex health issues, requiring the parents to stay on site would ensure that their medical needs were met, toileting needs could be addressed, and any behavioral issues could be intercepted.

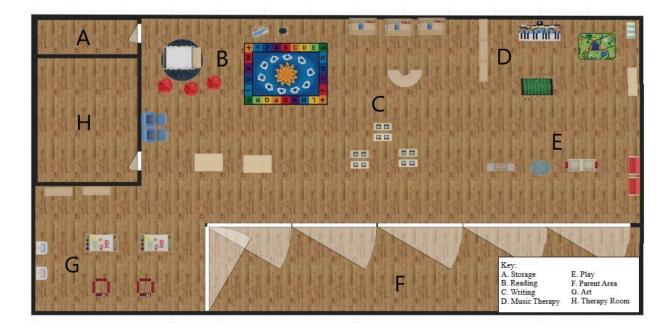


Figure 6: H-BLC Initial Floor Plan

## Visual Representation

Figure 7 is a visual created to show how the four goal components of the H-BLC will be achieved through utilizing the five main elements of PYD and the "Big 3" characteristics of an effective PYD program (Lerner, 2004).

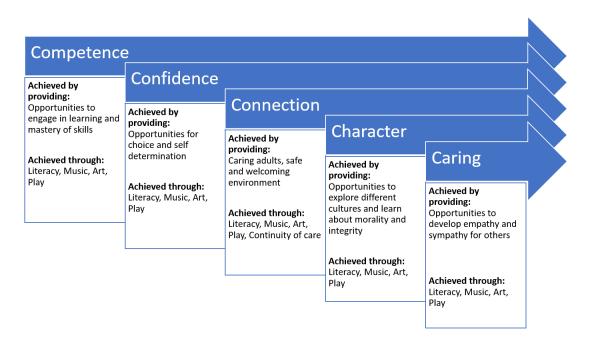


Figure 7: H-BLC Goals and Framework Adapted from Cochran, Arnett, and Ferrari (2006).

#### Summary

Chapter Two discussed the rationale for using the Positive Youth Development model as the framework for the H-BLC. Justification for the inclusion of the four main components; literacy, art, music, and play were augmented by the literature base. A physical layout of the H-BLC was developed and included in the presentation to be given to the focus group. A visual representation of the proposed components of the H-BLC was included.

### **CHAPTER THREE: FOCUS GROUP**

The purpose of this dissertation in practice was to develop a hospital-based learning center (H-BLC) for chronically ill children that would bridge the gap between long-term hospital stays and the return to school. In order to design a model that would meet the needs of the community context, stakeholders, and students, it was necessary to solicit feedback on the proposed model from stakeholders at various stages in the design process. To accomplish this, it was essential to conduct focus groups with stakeholders as participants to include them in the design process of the H-BLC.

"Focus groups represent a popular way to conduct interviews" (Cresswell, 2016, p. 127). The groups typically include six to eight individuals, encourage contributions from participants, and result in multiple sharing of ideas. Focus groups can be complex as it pertains to careful recording of participant input for accuracy (Cresswell, 2016). The researcher engaged a note taker and used a recording program, AudioNote, which allowed the researcher to record notes directly on the transcript as it was recorded.

#### Focus Group Participant Demographics

Participants in the focus group were selected to include those with a broad spectrum of knowledge of working with children with chronic illnesses. Table 4 provides demographic information of the focus group contributors. Entities from the hospital were asked to participate and those departments (music therapy and child life) selected their own representative. The remaining participants in the focus group were individually chosen for their expertise.

Table 4: Focus Group Demographics

Participant	Gender	Age	Role
Number		Range	
1	Female	55-59	Director – Center for Research in Education, Arts,
			Technology and Entertainment (CREATE) - University
			Partner
2	Female	30-34	Art Instructor – CREATE - University Partner
3	Female	40-44	Literacy Specialist – local school district
4	Male	25-29	Certified Music Therapist
5	Female	20-24	Music Therapy Intern
6	Female	30-34	Certified Child Life Specialist
7	Male	45-49	Hospital Family Centered Care Consultant and
			Parent of a child with a chronic illness
8*	Female	30-34	Hospital Program Manager for Medically Complex
			Children
9*	Female	45-49	Instructional Designer – CREATE - University Partner

<sup>\*</sup> Participants were not present for the initial focus group meeting due to scheduling but participated in both virtual reviews.

The focus group convened for three main sessions. Session One was a physical in-person meeting to learn the rationale of the model design and to provide input on its current plan and propose changes. The final two sessions were asynchronous, virtual meetings through a secure online portal called Webex that were conducted within six weeks of the initial session.

## Focus Group Process

An overview of the focus group process in its entirety can be found in Figure 8.

Participants in the focus group met in a conference room at AdventHealth for Children on March 26, 2019. Upon arrival, each participant received a number to identify themselves and the consent document was reviewed and affirmed. The initial model design was presented to the focus group in the form of a PowerPoint presentation. This presentation detailed the rationale for the inclusion of the four main components; literacy, music, art, and play and an example of the

physical space. The conversation then turned to what would be included in these four main components, and a review of the physical space was conducted.

There was a list of pre-established sample questions submitted with the IRB proposal (Appendix C) which served as guiding questions for all the interactions with the focus group. The natural flow of the conversation allowed these questions to be addressed throughout the focus group, although not in the anticipated format. The transcript of the in-person focus group meeting was then coded by the researcher and that data sorted into topical categories. The following information obtained from this focus group is reported and aggregated by topic.

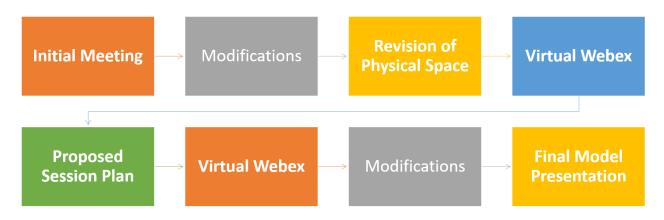


Figure 8: Focus Group Process

### Literacy

In the presentation of the Hospital-Based Learning Center (H-BLC) and the justification for the literacy component, one idea for a literacy activity was to have a local, dynamic storyteller come in and tell interactive stories to the students. There were no other specific literacy activity suggestions made by the focus group during the duration of the meeting; however, there was discussion about why literacy was chosen over other academic areas.

Literacy activities provide essential skills that would benefit all children and literacy experiences could be easily tailored to the physical and cognitive needs of each student.

Participant 3 (Literacy Specialist) wondered about the availability of books, as the physical layout showed only a small bookshelf. The group discussed the importance of having access to books and wanted to explore grant programs so the H-BLC students would have an expansive library on site and books to take home to read. Participant 3 also advocated for the inclusion of a puppet stage and puppets to encourage additional practice on retelling stories using puppets. Retelling stories through puppetry reinforces comprehension and helps develop speaking and listening skills.

#### Art

Participant 2 (Art Instructor- CREATE) displayed the art kits developed by CREATE to demonstrate the supplies and activities that could be done with the included materials. All the materials can be sanitized and stored for individual use. The art kits are one per student as to prevent cross contamination, and the kits can go home with the students so they can participate virtually when they are unable to attend a session at the H-BLC.

Participant 2 provided several art lesson examples – some with ties to literacy activities and some strictly art focused. The examples presented included an activity where the students would read a poem by Shel Silverstein and then draw an illustration to go with the poem. After the completion of the illustration, the students would compare and contrast their illustration with the illustrations from the author. Participant 2 also displayed examples of "Paint by Sticker" activities where the students would use stickers to create predetermined pictures.

One of the more versatile materials in the art kits were the watercolor pencils which can be used as colored pencils to draw. With the addition of water in a watercolor brush on top of the artwork, the drawing becomes a watercolor painting. The example shown was for emergent readers learning letters of the alphabet and was a coloring page involving the letter "O." Should a student not have the dexterity to color well, due to skill set or medical condition, the coloring part of the process could be done by a sibling or a parent. The water painting portion could then be done by the student regardless of fine motor control due to the broad handle of the brush and the forgiving nature of the watercolors. Additional activities described were making an abstract butterfly by dropping colors on filter paper and adding drops of rubbing alcohol to blend the colors and an art lesson on shading and color families.

Participant 1 (Director-CREATE) followed Participant 2's demonstration by explaining how art created by children can be indicative of their social-emotional wellbeing. She stated, "Sometimes if they're not well, that comes out in the art. If they're happy, it comes out in the art."

#### Music

Participant 4 (Certified Music Therapist) recommended that the duration of a group experience for this age should be between fifteen and thirty minutes. He also suggested the private room we had designated for play therapy, be available for individual music therapy as well. He envisioned a group music therapy session to work on a targeted skill, such as relatedness, with less structure and more improvisation as that would be helpful for achieving that goal. When necessary, there would be opportunities for individual sessions. Participant 4

also recommended a set of musical instruments that could be left inside the H-BLC. Leaving the instruments in the H-BLC would allow a Music Therapist access to instruments without having to bring the inpatient hospital set over reducing cross contamination. Additionally, Participant 4 also recommended that there be a storage cabinet designated for instruments to be secured.

## Play

Participant 6 (Certified Child Life Specialist) briefly detailed the role of a child life specialist. The focus of a child life specialist is to provide psychosocial-emotional support for children while in the hospital. Child life works to normalize a child's hospital stay and provides children ways to cope through play. One of Participant 6's proposed additions to the play component of the H-BLC was the inclusion of several medical play items specific to this population - such as IV poles, pretend MRI machines, and other medical play items. Having medical devices (feeding tubes, oxygen, IV pumps) often make children feel isolated but are necessary for survival. These interactions allow children to find common ground while playing with medical equipment and foster a sense of belonging where medical devices are common and not unusual.

Participant 6 endorsed the addition of puppets and a puppet stage to be used for role playing activities and as an alternative way for children to communicate their feelings. She also recommended the addition of an outdoor space (simulated or real) to allow students opportunities to play while experiencing the outdoors, weather, sunlight, and other natural things they may be missing due to their recovery. Further, Participant 6 was a proponent of providing opportunities for students to interact with basic materials such as dirt, sticks, and sand as those interactions are

beneficial for brain development. She discussed the notion of "risky play," which allows children to take risks in a controlled environment and learn about cause and effect.

The focus group was confused about the difference between the type of play that a Child Life Specialist would conduct, and what interactions defined Play Therapy. The researcher gave a brief overview on the distinction between the two. Participant 6 stated that having a way to identify children in need of further mental help would be an additional benefit of the H-BLC.

## Technology

Certain technology resources were already integrated into the H-BLC model programming. However, to elicit more specific items and programs, the following question was posed to the focus group: "For the kindergarten through fifth grade student population, what kind of technology items do you think we should have in this center, and what should we avoid?" Participant 2 (Art Instructor-CREATE) advocated for the inclusion of 3Doodler pens, which are hand-held 3D printers. While technically this device falls under the auspices of an art tool, it can be used to create many more thematic based items which allows it to be integrated into the center.

Participant 1 (Director-CREATE) recommended that we use Quiver. This program is an augmented reality program in which students create a drawing, print it out, and then scan a QR code allowing Quiver to bring their drawing to life. Participant 1 also encouraged the use of virtual reality goggles to provide additional unique experiences for this student population. These students would be able to return to their schools having had an exclusive technological experience that they can share with their classmates. Physical and cognitive limits might interfere

with a student's use of virtual reality goggles, so Participant 3 (Literacy Specialist) suggested the use of Google Expeditions to take the students on virtual fieldtrips. To do this, a large screen - via projector or large TV would be needed. As these are students for whom travel might be difficult, virtual field trips would be beneficial to allow exploration without having to physically travel. These technical innovations could provide unique ways for students to interact with other students in the H-BLC.

## Physical Space Review

The researcher provided a design for the physical space in a visual representation of the H-BLC, which resulted in an in-depth discussion on what should be included both physically and programmatically. Samples of the initial physical layout photos presented to the focus group are found below in Figures 9-12.

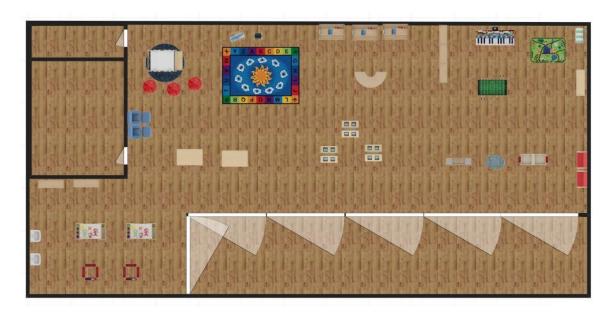


Figure 9: Initial H-BLC Floorplan



Figure 10: Initial View from Parent Area



Figure 11: Initial Art Area



Figure 12: Initial Play Area

Throughout the focus group process, the group had many suggestions of what to add to the physical design space. These recommendations can be divided into two main categories; physical items to be included, and adaptations to the physical space. The suggestions that the group made pertaining to items that were missing from the physical setting, and therefore missing from the programmatic setting were: puppets and a puppet stage, a projector or large TV, a printer, medical play items such as a play MRI table, additional books in the reading area, and additional musical instruments and instrument storage.

The group felt that the physical space needed light and color. Participant 3 (Literacy Specialist) suggested large windows to allow for as much natural light as possible. Collectively, the group agreed that there was a need for an outdoor setting - whether real or simulated. There was a suggestion made by Participant 1 (Director-CREATE) to use AstroTurf or an assortment of different flooring textures to provide an additional sensory element to the H-BLC. Participant

6 (Certified Child Life Specialist) suggested that an outdoor play area would allow the students to participate in "risky" play – opportunities to challenge themselves in a safe, supportive environment.

#### Parent Area

The focus group agreed that locating the parent area behind one-way glass would be beneficial for fostering student independence. Parents could not be seen by the H-BLC participants during a session, but would be available to address any medical, behavioral, or personal care issues that might arise. This parent area would contain couches, coffee, and snacks and seating conducive for parental interaction. The group also believed it was important to include an area for parents who did not feel like socializing that would allow for quiet and limited interaction. Additional suggestions made by the group for the parent area were to provide programming intended to address parental stress. Some ideas were to have chair massages for the parents, classes on applying for Medicaid waiver and other government programs, and providing healthcare professionals to address unmet health needs of this parent population while their children were attending the H-BLC.

#### Feedback on Center Use

Participant 4 (Certified Music Therapist) inquired about the timing of sessions and use of the center. The hours of the sessions would need to be regularly scheduled so that parents would be able to plan for those times and not schedule other appointments at the same time. One idea was to suggest parents schedule a medical appointment before or after the H-BLC session (since the outpatient providers would be located nearby) so that only one trip to the hospital facility

would be necessary. Due to the complex nature of these children's medical needs, a 60-90-minute session per day was recommended by the group as the maximum time frame for a single session. There were differing opinions about optimal group size. Participant 2 (Art Instructor-CREATE) said ideally there would be eight participants at one time. Participant 4 (Certified Music Therapist) said that eight participants would work, but that four to six would be better. Participant 6 (Certified Child Life Specialist) said that four to six would be best. As the focus group recommended that the maximum participants be limited to six, the sessions could begin with a whole group literacy activity and then rotate smaller groups through the other H-BLC activities. This schedule removes the limit of six students total in one session and expands the number of students served to a maximum of eighteen.

Participant 4 (Certified Music Therapist) raised the question on how children would be referred to the H-BLC. One suggestion was to add a note to the child's medical record that would alert the H-BLC to an extensive recovery period that would keep them from school. This note would indicate to those ancillary inpatient services, Child Life and Music Therapy, to introduce the H-BLC program and signal those services to introduce themselves to promote a continuity of care as the child transitions from inpatient to outpatient.

#### Inclusion of Technology

Although technology had been included in the plans for the H-BLC, originally it was slated to be integrated within the four main components of the H-BLC model. Through discourse with the focus group, a strong case was made for many technological products and innovations. It became apparent that technology needed to be added as an additional component in this model.

Not only will these technology resources assist in supporting the other four modalities they would also allow collaborative ways to connect H-BLC students to their home school and to other H-BLC students. One of the group ideas was to provide tablet devices to students while they are sick at home or inpatient so they could participate with their friends on the various activities held during a session at the H-BLC.

### Sustainability

Prior to the focus group meeting, the question of sustainability was posed by a hospital entity who provides initial funding for collaborative health projects. This question was then shared with the focus group. The group suggested to examine local community resources, inquire about their funding sources, pursue grants, and work to locate donors. Participant 4 (Certified Music Therapist) proposed that examining the outcomes for H-BLC students and parents might result in a higher level of support from the hospital system. For example, if the H-BLC was able to prove that it was having a positive impact on both parties, then perhaps it might earn budgeting or foundational support.

### **Interdisciplinary Collaboration**

Originally, the design of the center included a series of separate literacy, art, music therapy, and play sessions possibly centered around a common theme. Participant 6 (Certified Child Life Specialist) said it best when she said, "There're such great opportunities for us to all work together!" Out of the focus group discussion came the realization that the H-BLC activities needed to be interdisciplinary and not isolated sessions. Not only would this allow students to translate their new skills over a variety of domains, but it would also allow the various entities

(music therapy, art, child life) opportunities to collaborate in a way they are seldom able to do in this hospital setting. This interdisciplinary structure will give the program more opportunities to connect children in a variety of ways.

# Virtual Meetings and Design Reviews

Webex is an online virtual meeting space program created by Cisco Systems that is used for collaborative projects. There are opportunities for live and recorded sessions, but due to scheduling difficulties – the notion of a live virtual session was discarded, and a different component of the Webex software was used. Webex Teams (Figure 13) is a virtual team meeting space that allows users to invite participants to use a chat room, upload documents for review, and create videos (Cisco Systems, 2019). Due to its asynchronous nature, this meeting space was used to present both the revised physical space and the proposed session plan. After the initial inperson focus group session, there were two asynchronous virtual meetings via Webex Teams that allowed the participants to view the changes made on the physical layout, examine a proposed interdisciplinary session plan, and provide any final feedback prior to the study's completion.

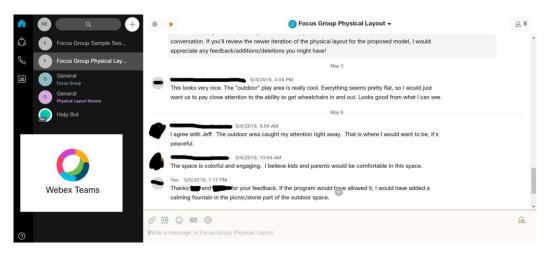


Figure 13: Webex Teams Chat Feature

The revised physical layout was uploaded to the group on Webex Teams for review. The documents provided were a floor plan of the revised physical layout, rendered photos of each of the five main component areas, and a list of changes extracted from the focus group feedback. All nine participants reviewed the physical layout. The amount of feedback received from the revisions to the physical layout was minimal, but very complimentary. The additions made based on the focus group data were well received. Participant 8 (Hospital Program Manager) suggested that we ensure that the H-BLC flooring is level and wheelchair accessible for those students who have mobility needs and medical equipment requirements.

The proposed interdisciplinary sample session plan centered around the theme of "Ancient Egypt" which was a proposed thematical topic briefly discussed during the focus group meeting. This interdisciplinary session included two activities for each of the five main components. This sample session template was uploaded to the Webex Teams interface for the group to review. Participants 1, 3, and 7 complemented the interdisciplinary nature of the proposed session. The overall focus group response to the proposed session was positive with minor issues noted by Participant 3. Participant 3 (Literacy Specialist) observed that two of the Florida Standards were not applicable and provided alternative standards to use instead. The standards used were from the "Reading Standards from Informational Texts" domain and the story used was not an informational text, rendering those standards inapplicable in this portion of the session. Participant 3 also recommended that the students review the original Cinderella story (in print or video format), prior to reading The Egyptian Cinderella by Shirley Climo so they could accurately compare and contrast these two stories. These changes were made to the proposed sample session plan which is included in the following chapter.

# **Summary**

Chapter Three detailed the steps taken to acquire data from a focus group comprised of hospital professionals, school district and university partners, and a parent of a chronically ill student. The data obtained from the focus group was aggregated by topic. Focus group input resulted in the need to add technology as its own component to the H-BLC and the need for interdisciplinary collaboration among providers to ensure all H-BLC student needs are addressed. The final physical layout and proposed session plan created and modified from the focus group and subsequent review process is included in the next chapter.

#### **CHAPTER FOUR: FINAL MODEL DESIGN**

The Dissertation in Practice is designed to present a research-based problem of practice related to, or in the field of, education. The goal of the work is to present the problem and, based upon examination of related literature and research, design a program, a model of work focused on the problem, or a program evaluation as possible solutions or improvements. Research into solution-building results in theoretical or conceptual frameworks that form the foundation of the goals and outcomes of the work and the rationale for choices of the researcher in the design of the program, model or program evaluation. The problem of practice addressed in this Dissertation in Practice was the absence of social and academic opportunities provided by the hospital homebound setting.

This chapter presents the final version of the Hospital-Based Learning Center (H-BLC). Feedback from stakeholder focus groups consisting of hospital professionals (music therapy, child life, and family-centered care), school district partners (literacy), university partners (CREATE), and a parent of a chronically ill student led to the development of the final model. The feedback process consisted of stakeholder focus groups that reviewed the preliminary model including a physical layout and planned activities tailored for chronically ill students. The first focus group was held in the hospital facility with focus group participants. Subsequent focus groups used the technology application, Webex Teams, for participants to review and provide feedback on the proposed model design. The researcher applied data gathered from face-to-face and web-based meetings to the final design of the proposed H-BLC. The final model also includes an explanation of how the theoretical foundations were applied.

### **Theoretical Foundations**

The primary theoretical framework that guided the development of the H-BLC was Bronfenbrenner's (1979, 2005) Ecological Systems Theory (EST), which posits that development is a product of the interaction of a person and their environment. Out of this theory, Positive Youth Development (PYD) became the moniker for programs aimed at focusing on opportunities to develop positive behaviors in environments that are conducive to growth and development. Lerner (2004) noted three essential characteristics of effective PYD programs: sustained positive relationships between a child and caring adult, life skills acquisition, and opportunities for leadership and service. Table 5 highlights the ways that the H-BLC model addressed these essential three characteristics. The model presented in this dissertation in practice is designed to integrate the elements of PYD: competence, confidence, connection, character, and caring, with the three essential characteristics. Figure 14 redefines each PYD components and provides an example of an H-BLC activity to address each.

Table 5: H-BLC and the "Big Three" Essential PYD Criteria

<b>According to Lerner</b>	Characteristics of the H-BLC model		
(2004) effective PYD			
programs have:			
sustained positive	By providing opportunities for students to interact with several H-		
relationships between	BLC facilitators, especially the child life and music therapy teams,		
a child and caring	they can continue to develop those positive relationships that can be		
adult	sustained both in the hospital and out of the hospital.		
	The focus on literacy includes opportunities to hone reading, writing,		
life skills acquisition	speaking and listening which are all valuable life skills. Additional		
	peer interaction increases communication skills.		
opportunities for	By providing opportunities through the various therapeutic modalities		
leadership and	for students to have personal freedom and take on leadership roles.		
service	Several service projects will be included in the programming such as		
	toy drives, supportive notes to patients in the hospital.		



Figure 14: H-BLC Activities That Address PYD

### Competence

Competence is the first of the PYD elements addressed by the H-BLC model. This PYD element focuses on positive views of one's abilities in several domains - social, academic, and vocational. (Geldhof et al., 2014). The H-BLC model provides opportunities for learning and skill mastery. One example involves a literacy activity in which students will read a short story about hieroglyphics – the formal writing symbols used by Ancient Egyptians. Using word analysis and phonics to identify the sounds in their name, they will use hieroglyphic stamps to write their names. Students will also receive a hieroglyphic alphabet document to take home to continue to practice writing new words. Learning a new skill, such as writing in hieroglyphics,

increases a student's positive view of their academic abilities which may lead to an increased feeling of competence.

#### Confidence

Confidence is the second element of PYD addressed by the H-BLC model. Where competence is the positive belief in one's abilities in domain specific areas, confidence is a positive belief in self – both in self-worth and self-efficacy (Geldhof et al., 2014). The H-BLC model provides opportunities for choice and self-determination to address this element of PYD. A music therapy activity to address this element would be introducing students to the song and dance to "Walk like an Egyptian" by the Bangles. Each student would get the chance to develop their own unique "walk" or signature move and teach it to the group. The group will then incorporate everyone's particular "walk" into the song. This activity promotes confidence by encouraging participation and celebrating the uniqueness of each students' walk.

#### Connection

Connection is the third element of PYD addressed by the H-BLC model. Connection describes the positive bidirectional bonds a student may have with a peer, adult, or institution (Geldhof et al., 2014). The H-BLC provides opportunities for students to connect with caring adults and peers in a safe, welcoming environment. An example of a technology activity would be to introduce students to an unfamiliar technology device, a 3Doodler Pen, to create a 3D pyramid shape. Initial use of this device can be challenging, but in a safe, welcoming environment mistakes are opportunities to learn. Students are supported and encouraged by peers and caring adults while learning how to create a 3D object. Connection is also fostered in the H-

BLC by providing students with the continuity of care - interactions with caring adults from the hospital in an outpatient setting.

### Character

Character is the fourth element of PYD addressed by the H-BLC model. Geldhof et al. (2014) defines character as "respect for societal and cultural rules" (p. 934). The H-BLC model provides opportunities to explore differences, morality, and integrity through various programming. An example of an art activity would be decorating a sarcophagus. In Ancient Egypt, decorations on one's sarcophagus showed the items and ideals important to the person inside. Students decorate the outside of their sarcophagus (pencil box) with drawings or magazine cut-outs of items important to them and highlight their two most important items to the group. Not only is this activity beneficial for identifying key desires of a student, but the communication of those ideas to the group assists the group in understanding differences and similarities.

### Caring

Caring is the fifth and final element of PYD addressed by the H-BLC model. Caring is developing a sense of empathy and sympathy for others (Geldhof et al., 2014). The H-BLC model encourages this development by providing opportunities to develop empathy and sympathy for others through structured activities. An example of a play activity would be the use of puppets. Students play with puppets that were specially chosen for inclusion in the H-BLC because they all possess medical equipment similar to the students such as feeding tubes, oxygen, and prosthetics. Continuing the Ancient Egypt theme, these puppets would be dressed as

Egyptians, with the goal of students engaging in a conversation with each other about the pictures and decorations they chose to include in their sarcophagus design. Students gain insight into how other students are thinking and feeling through these puppet interactions.

### Session Plan Development

The proposed activities went through several different iterations. Initially, the sessions were not integrated and were intended to be a series of separate activities possibly centered around a common theme. There were a few issues with this format - primarily the chronically ill student population is known for its frequent absences. If an H-BLC student was unable to attend the music therapy session day, they would miss out on the benefits and opportunity for growth and development that would come from a music therapy session. Through the focus group interaction, I came to realize that although the inpatient entities, child life and music therapy, work with the same population – there were limited opportunities for them to program together. By creating interdisciplinary sessions, it would allow for collaboration between the modalities. H-BLC students who attend a session will be able to benefit from all five modalities and can continue to develop a positive adult-child relationship with multiple adults in one session.

These sessions will include several facilitators. The literacy activity would be a whole group activity that all the students would participate in together at the beginning of the session. The other four modalities would be on a rotational basis and occur after the literacy activity. Literacy, art, and technology are more flexible and do not necessarily require certification, although both a certified teacher and Registered Art Therapist would be preferred. The type of literacy, art, and technology activity would dictate the requirements of the facilitator. Music

Therapy and play activities need to be conducted by a Certified Music Therapist and a Certified Child Life Specialist who have the requisite skills to address the social-emotional needs of chronically ill students. As the H-BLC would be an extension of the hospital's existing music and child life programs, participation in the H-BLC program would be on a rotational basis using existing employees. In addition, for those students whose mental health needs exceed the scope of a Certified Child Life Specialist, a Registered Play Therapist would be included.

Table 6 is an example of one H-BLC session intended for use with upper elementary grades 3-5. It was developed around a centralized theme of Ancient Egypt and includes two activities from each of the five main components of the H-BLC. Each one of these activities addresses one or more components of the Positive Youth Development framework.

# <u>H-BLC Proposed Session</u>

Table 6 : H-BLC Session - Upper Elementary - Ancient Egypt

Program	Activity	Objective	Materials Needed	Florida ELA Grade 5	PYD
Component				Standards Addressed	Components
					Integrated
Literacy	Watch short video of original Cinderella story Read Story The Egyptian Cinderella	To compare and contrast this version of Cinderella with the original version of Cinderella.	<ul> <li>Short video recapping the original Cinderella story</li> <li>Book The Egyptian Cinderella</li> <li>Large piece of paper for Venn Diagram</li> <li>Chart to show new vocabulary (canopic jars, hieroglyphs, hieroglyphics, natron, pyramid, tomb, organs)</li> </ul>	LAFS.5.RL.1.3 Compare and contrast two or more characters, settings, or events in a story or drama, drawing on specific details in the text (e.g., how characters interact).  LAFS.5.RL.3.9 Compare and contrast stories in the same genre (e.g., mysteries and adventure stories) on their approaches to similar themes and topics.  LAFS.5.L.1.1 Demonstrate command of the conventions of standard English grammar and usage when writing or speaking.	Connection Competence

Program Component	Activity	Objective	Materials Needed	Florida ELA Grade 5 Standards Addressed	PYD Components Integrated
Literacy	Writing in Hieroglyphics	To write in Hieroglyphs.	<ul> <li>Book Fun with Hieroglyphs</li> <li>Hieroglyphics Chart showing letter sounds (laminated)</li> <li>Hieroglyphic Stamps</li> <li>Paper</li> <li>Ink</li> <li>Baby wipes</li> </ul>	LAFS.5.W.3.9 Draw evidence from literary or informational texts to support analysis, reflection, and research.  LAFS.5.RF.3.3 Know and apply grade-level phonics and word analysis skills in decoding words.	Competence Confidence
Art	Canopic Jars	To learn about the purpose of canopic jars and construct one.	<ul> <li>Reference page 10-11 from You Wouldn't Want to be an Egyptian Mummy</li> <li>Small Pringles Cans</li> <li>Construction Paper</li> <li>Egyptian Canopic Jar Examples</li> <li>Air Dry Clay (art kit)</li> <li>Markers (art kit)</li> <li>Glue (art kit)</li> <li>Scissors (art kit)</li> </ul>	LAFS.5.W.3.9 Draw evidence from literary or informational texts to support analysis, reflection, and research.	Connection Character
Art	Sarcophagus Pencil Box	To decorate a pencil box and show items and ideas that represent themselves and things that are of importance.	<ul> <li>Sarcophagus Pencil Boxes</li> <li>Magazines</li> <li>Markers (art kit)</li> <li>Glue (art kit)</li> <li>Scissors (art kit)</li> </ul>		Connection Caring Confidence

Program Component	Activity	Objective	Materials Needed	Florida ELA Grade 5 Standards Addressed	PYD Components Integrated
Music	Fun with Dorian Scale	To compare the Dorian scale to a major scale.	Assorted instruments		Character Connection
Music	Walk Like an Egyptian song/dance	To participate in a shared musical/movement experience.	Assorted instruments		Confidence Character Connection
Play	Turn doll into a mummy.	To use medical supplies to "mummify" a doll.	<ul> <li>Old Dolls</li> <li>Adhesive bandage wrap</li> <li>Reference pages 14-15 from You Wouldn't Want to be an Egyptian Mummy</li> </ul>	LAFS.5.W.3.9 Draw evidence from literary or informational texts to support analysis, reflection, and research.	Caring Connection
Play	Egyptian Mummy Puppets	To use puppetry as a form of play to engage in a conversation with other students about how their sarcophagus pencil box describes represents them.	<ul> <li>Medical Puppets</li> <li>Egyptian Costumes</li> <li>Puppet Stage</li> </ul>		Connection Caring
Technology	Virtual Fieldtrip	To visually explore Egypt through virtual sightseeing.	<ul><li>Large Screen</li><li>Virtual Field Trip resources</li></ul>		Connection Competence
Technology	3D Pyramids	To use a new medium (3D filament) to create a 3D pyramid.	<ul><li> 3Doodler Pens</li><li> Filament</li><li> Template for pyramid</li></ul>		Competence Confidence Connection

### Final Physical Layout Design

The physical layout was originally constructed to facilitate the discussion with the focus group about what programmatic elements and physical attributes should be included in the center. The focus group evaluated the physical layout twice, once in the face-to-face meeting and the second through Webex Teams. The H-BLC final floorplan can be found in Figure 15.



Figure 15: Final H-BLC Floorplan

- A: Outdoor simulated picnic area
- B: Literacy
- C: Music Therapy
- D: Technology
- E: Storage
- F: Multi-use private office space (individual therapies)
- G: Storage
- H: Parent Area
- I: Art Area
- J: Multipurpose Tables
- K Play Area
- L: Outdoor simulated play area

The final physical layout for the H-BLC model includes several elements modified from focus group data. A large screen television was added for use for virtual fieldtrips. The number of available books were increased in the literacy area. A puppet stage was included to be used by both the literacy and play areas. On the suggestion of a focus group participant, the flooring now provides several different tactile elements by including stone, artificial grass, hardwood, carpet, and tile. The software used to create the final physical layout had some limitations and would not allow for the inclusion of the following items also suggested by the focus group: virtual reality goggles, 3D pens, puppets, play MRI machine, IV pole, and additional musical instruments.



Figure 16: Simulated Outdoor Area

Medical devices and physical functionality may prevent some students from participating in outdoor activities. One of the main additions to the H-BLC model garnered from the focus group interaction was the creation of a simulated outdoor play space (Figure 16). This area

contains artificial grass, three planter boxes for garden exploration, a sandbox, and a playhouse. This space is surrounded by large windows allowing for maximum exposure to natural light. This area provides the opportunity for students to experience learning in a pseudo-outdoor setting in a climate-controlled environment. Additionally, as AdventHealth has a partnership with Disney, this "outdoor" space might be modified to appear to be more realistic. Having an indoor space that simulates the outdoors would also allow this model to be used in other climates.



Figure 17: Play Area

The play area now contains several medical play items including a hospital bed and exam table (right side of Figure 17). Additional items such as an IV pole and a play MRI scanner will be included but due to limitations in the design software, they were unable to be added to the

photo of the play area. Of note, the coffee table located in the front right of the picture is a fish tank which will allow students to participate as fish caretakers.

### Implications for the future

The H-BLC model space and resources could be used for additional populations. Future expansions of the H-BLC program could include increasing the age range of the center's population to include middle school and high school students. When not in use for chronically ill students, it could be used for other outreach programs such as community music therapy programs, art programs, and special events where the play space could be used to occupy students while parents attended sessions in the parent area. Expanding the Play Therapy component would also allow for additional student's mental health issues to be addressed.

In addition to the previously mentioned university and hospital partners, there would also be additional opportunities for partnerships and collaborations. A way to encourage reading would be to have a satellite library stocked by the county public library system. Adaptations to session activities could be customized for each child's unique situation by consulting and collaborating with special education teachers from Orange County Public Schools or AdventHealth Physical Therapy or Occupational Therapy units. The H-BLC students could partner with local community agencies to participate in service events.

Through countless discussions in hospital hallways with families, various literature resources, and focus group data, it became clear that while the interventions posed by the H-BLC model would address the academic and social needs of chronically ill students, more resources and programs targeted at parents were critical for reducing toxic stress exposure. This led to the

future concept of adding a pediatric respite facility in the same location as the H-BLC. Modeled after a similar program located in Phoenix, Arizona called the Ryan House (Ryan House, 2019), this respite program would allow families to admit their child into the facility for a short duration of time. The child's medical needs would be met by medical professionals and their social-emotional needs would be addressed by child life and music therapy. This respite would allow overtaxed families the ability to have time off, travel to places usually inaccessible with their complex child, or allow them to relax and rest and alleviate the stress faced by the daily care of a child with complex medical needs. This respite facility would also utilize the H-BLC space for additional learning and technological experiences.

There are a myriad of research opportunities that could lead to innovative findings and additional funding sources should the H-BLC model come to fruition. An opportunity might be to examine the impact of continuity of care (same facilitators in and out of the hospital) on positive adult-child relationships. The majority of the literature regarding Positive Youth Development focuses on teenagers. Examining the applicability of the Positive Youth Development framework to the elementary aged population would establish if participating in a PYD program elicits the same targeted positive behaviors (such as competence, confidence, etc.). Researching the academic and social-emotional outcomes of participating in the H-BLC program and what impact participation might have on school re-entry would be additional valuable data.

### Researcher Reflections

From my positionality as a researcher and as a mother of a chronically ill child, I have hope that this model will be implemented soon. This program has the capacity to alter academic,

social-emotional, and long-term outcomes for many students - including my son. There are many challenges presented due to his health and prognosis, but none as heartbreaking as his feeling that he does not have friends because he cannot attend school. Being a caregiver to a child with special needs is so isolating, and with no respite care, opportunities for interacting with other adults are limited. While he could attend sessions in the H-BLC, I would have the opportunity to meet other parents facing similar battles and we would all benefit from resources the H-BLC would provide. This project has given me purpose and direction and I am dedicated to pursuing all avenues to make the H-BLC a reality.

### Conclusion

This dissertation in practice examined the literature and a sample of existing programs that addressed the educational and social-emotional challenges of students with chronic illness in order to bridge the gap between hospital discharge and school re-entry. Literature showed that the hospital homebound setting was problematic for chronically ill students due to minimal hours of academic instruction and little interaction with peers (Madan-Swain et al., 2004). Students with chronic illness were at higher risk for maladaptive behaviors, lower educational attainment, and higher use of social services (Maslow et al., 2012). Programs created at other facilities to address this problem were reviewed for pertinent information such as funding sources, location, division of responsibility, and relationships with school districts. Those findings were incorporated into a Hospital-Based Learning Center (H-BLC) model designed to address both the academic and social-emotional needs of elementary students using the Positive Youth Development framework.

Positive Youth Development (PYD) grew out of Bronfenbrenner (1979) Ecological Systems Theory and became a framework for programs aimed at the development of positive behaviors in children while situated in environments that are conducive to growth. The model presented in this dissertation in practice is designed to integrate the components of PYD: competence, confidence, connection, character, and caring, with the three essential characteristics of an effective PYD program. Lerner (2004) noted three essential characteristics of effective PYD programs: sustained positive relationships between a child and caring adult, life skills acquisition, and opportunities for leadership and service.

The design process included a focus group of hospital professionals (music therapy, child life, and family-centered care), school district partners (literacy), university partners (art), and parents of chronically ill students. The focus group reviewed the model and provided feedback on the design based on their expertise and modifications were made by the researcher to the design. Webex-Teams, an online meeting platform, was used for stakeholders to review modifications to the physical layout and analyze a proposed sample interdisciplinary session plan. The final model design includes five components: literacy, art, music therapy, play, and technology, a physical floorplan, and an interdisciplinary session plan to address the academic and social well-being of chronically ill students. With financial and logistical support, the H-BLC program model could be replicated at any hospital facility.

#### Summary

Chapter Four provided the final version of the H-BLC model and how the model components addressed the main elements of the Positive Youth Development framework. The

findings of the focus group were incorporated and a sample session plan including all five program components (literacy, art, music therapy, play, and technology) was included.

Additionally, the final physical layout was presented with the modifications suggested by the focus group.

## **APPENDIX A: APPROVAL LETTER**



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#### **EXEMPTION DETERMINATION**

February 21, 2019

Dear Nicole Eggert:

On 2/21/2019, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Initial Study, Category
Title:	Bridging the Gap Between Hospital and School
Investigator:	Nicole Eggert
IRB ID:	STUDY00000214
Funding:	None
Grant ID:	None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or <a href="mailto:irb@ucf.edu">irb@ucf.edu</a>. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Racine Jacques Designated Reviewer

dr de

Page 1 of 1

# APPENDIX B: 5<sup>th</sup> GRADE ELA STANDARDS



# **English Language Arts Standards**

GRADE: 5

Strand: READING STANDARDS FOR LITERATURE			
Cluster 1: Key Ideas ar	nd Details		
STANDARD CODE	STANDARD		
LAFS.5.RL.1.1	Quote accurately from a text when explaining what the text says explicitly and when drawing inferences from the text.		
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts		
LAFS.5.RL.1.2	Determine a theme of a story, drama, or poem from details in the text, including how characters in a story or drama respond to challenges or how the speaker in a poem reflects upon a topic; summarize the text.		
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning		
LAFS.5.RL.1.3	Compare and contrast two or more characters, settings, or events in a story or drama, drawing on specific details in the text (e.g., how characters interact).		
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts		

Cluster 2: Craft and Si	tructure
STANDARD CODE	STANDARD
LAFS.5.RL.2.4	Determine the meaning of words and phrases as they are used in a text, including figurative language such as metaphors and similes.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts
LAFS.5.RL.2.5	Explain how a series of chapters, scenes, or stanzas fits together to provide the overall structure of a particular story, drama, or poem.
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.RL.2.6	Describe how a narrator's or speaker's point of view influences how events are described.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Cluster 3: Integration of	of Knowledge and Ideas
STANDARD CODE	STANDARD
LAFS.5.RL.3.7	Analyze how visual and multimedia elements contribute to the meaning, tone, or beauty of a text (e.g., graphic novel, multimedia presentation of fiction, folktale, myth, poem).  Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.RL.3.9	Compare and contrast stories in the same genre (e.g., mysteries and adventure stories) on their approaches to similar themes and topics.  Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Cluster 4: Range of Reading and Level of Text Complexity		
STANDARD CODE	STANDARD	
	By the end of the year, read and comprehend literature, including stories, dramas, and poetry, at the high end of the grades 4–5 text complexity band independently and proficiently.  Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	

Strand: READING STANDARDS: FOUNDATIONAL SKILLS (K-5)		
Cluster 3: Phonics and Word Recognition		
STANDARD CODE	STANDARD	
LAFS.5.RF.3.3	Know and apply grade-level phonics and word analysis skills in decoding words.  a. Use combined knowledge of all letter-sound correspondences, syllabication patterns, and morphology (e.g., roots and affixes) to read accurately unfamiliar multisyllabic words in context and out of context.	
	Cognitive Complexity: Level 1: Recall	

Cluster 4: Fluency	
STANDARD CODE	STANDARD
LAFS.5.RF.4.4	Read with sufficient accuracy and fluency to support comprehension.      Read on-level text with purpose and understanding.     Read on-level prose and poetry orally with accuracy, appropriate rate, and expression on successive readings.     Use context to confirm or self-correct word recognition and understanding, rereading as necessary.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Strand: READING STANDARDS FOR INFORMATIONAL TEXT Cluster 1: Key Ideas and Details			
STANDARD CODE	STANDARD		
LAFS.5.RI.1.1	Quote accurately from a text when explaining what the text says explicitly and when drawing inferences from the text.		
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts		
LAFS.5.RI.1.2	Determine two or more main ideas of a text and explain how they are supported by key details; summarize the text.		
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts		
LAFS.5.RI.1.3	Explain the relationships or interactions between two or more individuals, events, ideas, or concepts in a historical, scientific, or technical text based on specific information in the text.		
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning		

Cluster 2: Craft and St	ructure
STANDARD CODE	STANDARD
LAFS.5.RI.2.4	Determine the meaning of general academic and domain-specific words and phrases in a text relevant to a <i>grade 5 topic or subject area</i> .
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts
LAFS.5.RI.2.5	Compare and contrast the overall structure (e.g., chronology, comparison, cause/effect, problem/solution) of events, ideas, concepts, or information in two or more texts.
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.RI.2.6	Analyze multiple accounts of the same event or topic, noting important similarities and differences in the point of view they represent.
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning

Cluster 3: Integration of Knowledge and Ideas	
STANDARD CODE	STANDARD
LAFS.5.RI.3.7	Draw on information from multiple print or digital sources, demonstrating the ability to locate an answer to a question quickly or to solve a problem efficiently.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts
LAFS.5.RI.3.8	Explain how an author uses reasons and evidence to support particular points in a text, identifying which reasons and evidence support which point(s).
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.RI.3.9	Integrate information from several texts on the same topic in order to write or speak about the subject knowledgeably.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Cluster 4: Range of Rea	ding and Level of Text Complexity
STANDARD CODE	STANDARD

LAFS.5.RI.4.10	By the end of the year, read and comprehend informational texts, including history/social studies, science, and technical texts, at the high end of the grades 4–5 text complexity band independently and proficiently.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

### Strand: WRITING STANDARDS

## Cluster 1: Text Types and Purposes

Cluster 1. Text Types	
STANDARD CODE	STANDARD
LAFS.5.W.1.1	Write opinion pieces on topics or texts, supporting a point of view with reasons and information.
	<ul> <li>a. Introduce a topic or text clearly, state an opinion, and create an organizational structure in which ideas are logically grouped to support the writer's purpose.</li> <li>b. Provide logically ordered reasons that are supported by facts and details.</li> <li>c. Link opinion and reasons using words, phrases, and clauses (e.g.,</li> </ul>
	consequently, specifically). d. Provide a concluding statement or section related to the opinion presented.
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.W.1.2	Write informative/explanatory texts to examine a topic and convey ideas and information clearly.
	<ul> <li>a. Introduce a topic clearly, provide a general observation and focus, and group related information logically; include formatting (e.g., headings), illustrations, and multimedia when useful to aiding comprehension.</li> </ul>
	<ul><li>b. Develop the topic with facts, definitions, concrete details, quotations, or other information and examples related to the topic.</li><li>c. Link ideas within and across categories of information using words, phrases,</li></ul>
	and clauses (e.g., in contrast, especially). d. Use precise language and domain-specific vocabulary to inform about or
	explain the topic. e. Provide a concluding statement or section related to the information or explanation presented.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts
LAFS.5.W.1.3	Write narratives to develop real or imagined experiences or events using effective technique, descriptive details, and clear event sequences.
	<ul> <li>a. Orient the reader by establishing a situation and introducing a narrator and/or characters; organize an event sequence that unfolds naturally.</li> <li>b. Use narrative techniques, such as dialogue, description, and pacing, to</li> </ul>
	develop experiences and events or show the responses of characters to situations.
	<ul> <li>c. Use a variety of transitional words, phrases, and clauses to manage the sequence of events.</li> <li>d. Use concrete words and phrases and sensory details to convey experiences and events precisely.</li> </ul>

	e.	Provide a conclusion that follows from the narrated experiences or events.
<u></u>	<u>Cognitiv</u>	ve Complexity: Level 3: Strategic Thinking & Complex Reasoning

Cluster 2: Production and Distribution of Writing	
STANDARD CODE	STANDARD
LAFS.5.W.2.4	Produce clear and coherent writing in which the development and organization are appropriate to task, purpose, and audience. (Grade-specific expectations for writing types are defined in standards 1–3 above.)
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.W.2.5	With guidance and support from peers and adults, develop and strengthen writing as needed by planning, revising, editing, rewriting, or trying a new approach.
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.W.2.6	With some guidance and support from adults, use technology, including the Internet, to produce and publish writing as well as to interact and collaborate with others; demonstrate sufficient command of keyboarding skills to type a minimum of two pages in a single sitting.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Cluster 3: Research to	Cluster 3: Research to Build and Present Knowledge	
STANDARD CODE	STANDARD	
LAFS.5.W.3.7	Conduct short research projects that use several sources to build knowledge through investigation of different aspects of a topic.	
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
LAFS.5.W.3.8	Recall relevant information from experiences or gather relevant information from print and digital sources; summarize or paraphrase information in notes and finished work and provide a list of sources.  Cognitive Complexity: Level 2: Pecia Application of Skills & Concepts	
= = =	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
LAFS.5.W.3.9	<ul> <li>Draw evidence from literary or informational texts to support analysis, reflection, and research.</li> <li>a. Apply grade 5 Reading standards to literature (e.g., "Compare and contrast two or more characters, settings, or events in a story or a drama, drawing on specific details in the text [e.g., how characters interact]").</li> <li>b. Apply grade 5 Reading standards to informational texts (e.g., "Explain how an author uses reasons and evidence to support particular points in a text, identifying which reasons and evidence support which point[s]").</li> </ul>	
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning	

Cluster 4: Range of Writ	ing
STANDARD CODE	STANDARD

Write routinely over extended time frames (time for research, reflection, and revision) and shorter time frames (a single sitting or a day or two) for a range of discipline-specific tasks, purposes, and audiences.
Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning

### Strand: STANDARDS FOR SPEAKING AND LISTENING

# Cluster 1: Comprehension and Collaboration

STANDARD CODE	STANDARD
LAFS.5.SL.1.1	Engage effectively in a range of collaborative discussions (one-on-one, in groups, and teacher-led) with diverse partners on <i>grade 5 topics and texts</i> , building on others' ideas and expressing their own clearly.
	<ul> <li>a. Come to discussions prepared, having read or studied required material; explicitly draw on that preparation and other information known about the topic to explore ideas under discussion.</li> <li>b. Follow agreed-upon rules for discussions and carry out assigned roles.</li> <li>c. Pose and respond to specific questions by making comments that contribute to the discussion and elaborate on the remarks of others.</li> <li>d. Review the key ideas expressed and draw conclusions in light of information and knowledge gained from the discussions.</li> </ul>
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning
LAFS.5.SL.1.2	Summarize a written text read aloud or information presented in diverse media and formats, including visually, quantitatively, and orally.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts
LAFS.5.SL.1.3	Summarize the points a speaker makes and explain how each claim is supported by reasons and evidence.
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts

Cluster 2: Presentation of Knowledge and Ideas	
STANDARD	
Report on a topic or text or present an opinion, sequencing ideas logically and using appropriate facts and relevant, descriptive details to support main ideas or themes; speak clearly at an understandable pace.	
Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
Include multimedia components (e.g., graphics, sound) and visual displays in presentations when appropriate to enhance the development of main ideas or themes.  Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
Adapt speech to a variety of contexts and tasks, using formal English when appropriate to task and situation.  Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	

	and: LANGUAGE STANDARDS ster 1: Conventions of Standard English	
STANDARD CODE	STANDARD	
LAFS.5.L.1.1	Demonstrate command of the conventions of standard English grammar and usage when writing or speaking.	
	<ul> <li>a. Demonstrate fluent and legible cursive writing skills.</li> <li>b. Explain the function of conjunctions, prepositions, and interjections in general and their function in particular sentences.</li> <li>c. Form and use the perfect (e.g., I had walked; I have walked; I will have walked) verb tenses.</li> <li>d. Use verb tense to convey various times, sequences, states, and conditions e. Recognize and correct inappropriate shifts in verb tense.</li> <li>f. Use correlative conjunctions (e.g., either/or, neither/nor).</li> </ul>	
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
LAFS.5.L.1.2	Demonstrate command of the conventions of standard English capitalization, punctuation, and spelling when writing.	
	<ul> <li>a. Use punctuation to separate items in a series.</li> <li>b. Use a comma to separate an introductory element from the rest of the sentence.</li> <li>c. Use a comma to set off the words yes and no (e.g., Yes, thank you), to set a tag question from the rest of the sentence (e.g., It's true, isn't it?), and to indicate direct address (e.g., Is that you, Steve?).</li> <li>d. Use underlining, quotation marks, or italics to indicate titles of works.</li> <li>e. Spell grade-appropriate words correctly, consulting references as needed.</li> </ul>	
	Cognitive Complexity: Level 1: Recall	

Cluster 2: Knowledge of Language		
STANDARD CODE	STANDARD	
LAFS.5.L.2.3	Use knowledge of language and its conventions when writing, speaking, reading, or listening.  a. Expand, combine, and reduce sentences for meaning, reader/listener interest, and style.  b. Compare and contrast the varieties of English (e.g., dialects, registers) used in stories, dramas, or poems.	
	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning	

Cluster 3: Vocabulary Acquisition and Use		
STANDARD CODE	STANDARD	
LAFS.5.L.3.4	Determine or clarify the meaning of unknown and multiple-meaning words and phrases based on grade 5 reading and content, choosing flexibly from a range of strategies.  a. Use context (e.g., cause/effect relationships and comparisons in text) as a clue to the meaning of a word or phrase.  b. Use common, grade-appropriate Greek and Latin affixes and roots as clues to the meaning of a word (e.g., photograph, photosynthesis).  c. Consult reference materials (e.g., dictionaries, glossaries, thesauruses), both print and digital, to find the pronunciation and determine or clarify the precise meaning of key words and phrases.	
	Cognitive Complexity: Level 2: Basic Application of Skills & Concepts	
LAFS.5.L.3.5	Demonstrate understanding of figurative language, word relationships, and nuances in word meanings.  a. Interpret figurative language, including similes and metaphors, in context. b. Recognize and explain the meaning of common idioms, adages, and proverbs. c. Use the relationship between particular words (e.g., synonyms, antonyms, homographs) to better understand each of the words.	
14505100	Cognitive Complexity: Level 3: Strategic Thinking & Complex Reasoning	
LAFS.5.L.3.6	Acquire and use accurately general academic and domain-specific words and phrases as found in grade level appropriate texts, including those that signal contrast, addition, and other logical relationships (e.g., however, although, nevertheless, similarly, moreover, in addition).  Cognitive Complexity: Level 1: Recall	

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# APPENDIX C: SAMPLE FOCUS GROUP QUESTIONS

# **Focus Group Questions**

Title of Project: Bridging the Gap Between Hospital and School

Principal Investigator: Nicole Eggert

Focus Group Meeting: After viewing proposed model components

Topic:	Sample Questions:
Services	What types of literacy, art, music, and play activities would you like to see
Provided	included in this center?
	How will the provided interaction by the H-BLC impact elementary-aged
	chronically ill students?
	Can you see any negative impacts from these types of engagement activities?
	What other services should be considered?
Physical	What elements need to be included in the physical layout for this model to be
Space	conducive and accessible for students of all physical needs?
	Any additional considerations?
Use	How should use of this facility be distributed?
	Where might additional resources be located?
	How should time be allocated?

**Webex Meeting 1:** After the initial focus group, the design model will undergo modifications based on focus group feedback. Focus group members will have the opportunity to review the revised design a second time virtually (in an asynchronous environment) through Webex and provide feedback.

Topic:	Sample Questions:
Services	Please review the sample literacy, art, music, and play activities and provide
Provided	feedback on each activity.
	What, if any, additional services do you believe should be included?
	Are there any additional suggested activities that need to be added to the list?
Physical	Please examine the revised physical layout of the space and provide
Space	feedback.
	Any additions or deletions?
TI	De deservice and the second section of the College
Use	Do these changes address your concerns about the use of the facility?
	Where might additional resources be located?
	How should time be scheduled?

### Webex Meeting 2: Final Model Presentation to Focus Group through Webex (asynchronous)

Topic:	Sample Questions:
Final	Any final feedback on the activities, physical space, or the proposed usage of
Feedback	the center?

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