

The Leadership Prize: APPLICATION

Part I: Preliminary Information

Title: Hospital to School: Transitions for Children with Special Healthcare Needs

Abstract: This research will evaluate inpatient care educational programs for children with special health care needs, and both hospitals and schools' capacity to effectively support these students as they transition back into school settings. This research aims to assess whether the current inpatient and outpatient systems effectively support children during their transition. In ineffective cases, I seek to understand methods that could improve such programs. To evaluate effectiveness, I will conduct semi-structured interviews with healthcare professionals, school nurses, teachers, social workers, and therapists. The research highlights the negative impact of low school attendance on medically fragile children. As a future special education teacher, the needs of this population are pertinent to my studies. This research therefore contributes to my professional development and is an opportunity to create positive change in the disability, education and healthcare communities by elevating students', teachers' and families' voices.

Part II: Problem Description and Personal Statement

1. Problem Description:

Current research indicates that 18% of all children live with a chronic illness, and 6.5% of these children suffer from an illness that is severe enough to keep them from attending school. Although there is no universal definition for children with special healthcare needs (CSHCN), they are often defined as “students who require complex health procedures, special therapy or specialized medical equipment/supplies to enhance or sustain their lives during the school day” (American Federation of Teachers, 2009, p. 1). Historically, CSHCN have often lived out their schooling years in a hospital setting, receiving academic instruction from their hospital beds. Hospitals were in charge of their academic, developmental and medical needs all at once. But as medical advancements have broadened, healthcare costs have risen significantly and the push for deinstitutionalization has grown. CSHCN are making the transition into their communities more frequently. The Individuals with Disabilities Act of 2004 (IDEA) has opened doors for CSHCN to reintegrate back into a school setting. IDEA provides children the right to a “free appropriate public education” in the “least restrictive environment” (American Federation of Teachers, 2009, p. 2). In the last half-century, the changes in the epidemiology of child health have become increasingly complex. This is in result of the health, education and social policy adaptations that have affected a struggling population. Because of this, gaps in service and care for children with special health needs have been identified (McPherson, 1998, p. 137). The Rehabilitation Act of

1973, Section 504 also advocates for the educational rights of CSHCN as it prohibits discrimination based on disability and requires federal-fund-receiving schools to provide accommodations to eligible students. This will allow them the same access to education as their peers without disabilities benefit from (Raymond, 2009, p. 188). In order to create a fully inclusive environment, the Rehabilitation Act of 1973 was implemented.

School is a setting where students are able to identify their own abilities, gain important relationships with their peers, and explore life outside of their home and family units. However, even when a CSHCN is granted resources and priceless experiences by the state, they are often too sick to attend school for long periods of time. This perpetual pattern of absence in the schools can be detrimental for CSHCN if they are not given the correct resources to succeed. In turn, their academic excellence decreases when they are not given proper schooling. According to the U.S. Department of Health and Services (2013), over 50% of children with special healthcare needs have missed three to over eleven days of school during one school year. Knauer (2015) identifies that the rates of attendance, high school graduation rates, and academic achievement are much poorer for students with special healthcare needs compared to their peers without healthcare needs. Twenty-one percent of school-aged CSHCN in California have repeated a grade, compared with eight percent of their peers without a special health need (Knauer, 2015, p. 326). Because of the many days that CSHCN must miss in order to deal with health-related issues, there is a perpetual pattern of being behind. If students are not caught up efficiently between these long spans of absences, they will fall permanently behind their peers and fail to stay on track in their future years of schooling.

A CSHCN often needs a large group of stakeholders in their academic success. The connections between these individuals are essential to the progress of a child with special healthcare needs. In an academic environment, the care of the child falls heavily on the special education or general education teacher as well as the school nurse. Their job becomes extensive but could be simplified with the assistance of medical professionals, school support staff and parent aid. (Pufpaff, et al. 2015, p. 685) (Raymond, 2009, p. 187). In order for children with special healthcare needs to have the most success in an academic environment, collaboration is vital. There is currently a missing link between the medical staff and the school staff that is fundamental to a student's achievement both academically and medically.

Hospital schools are one group that aids in the support of a child in the transition from hospital to school. By providing education during a hospital stay, hospital school teachers are able to keep students on task and caught up even when a child is missing many days of school. These individuals are then able to create a fluid process of re-entry for a child when they return to school. The problem that often appears is the disconnect between communication from the hospital to the school system and vice versa. Chesire (2011) details that the issue lies not within the ability of the school or hospital system, but in more complicated practices that these businesses are not upholding.

An insufficient transition program for children from the hospital setting to the school setting does not only negatively affect the child and family, but also the school and hospital systems as a whole. Without proper communication between liaisons from each community, no individuals are able to aid in the child's transition. This problem, however, does not have a simple solution. The school system must deal with the difficulties of insufficient funds, inadequate resources, and deficient infrastructure to name a few (Aruda et.al, 2011). The hospital is also challenged by patient care difficulties, lack of medical resources, and inaccessibility to in-need populations. The transition system for children moving from a hospital to a school or into homebound schooling is an immense process that involves many players. Without proper access from all sides, a child will be unable to integrate back into the school system.

2. Personal Background and Motivation:

I have spent many years in the hospital system when my dad suffered from a heart aneurysm and six days later, a stroke, that left him paralyzed and non-verbal. My family was forced to assume the role of caregiver for an individual who we used to see as invincible. As I spent time in these medical environments, I became interested in learning more about the pediatric programs in these hospitals. One rehabilitation hospital, in particular, sparked my interest. The Shirley Ryan Ability Lab (SRA) in Chicago has a unique and extensive pediatric program. As I got older, I involved myself in the workings of the pediatric floor and created and Junior board with over 200 members to raise money for the children in the hospital. In my junior year of high school, my interests deepened when I was given the opportunity to shadow the Chicago Public School teachers who were employed by SRA on the Pediatric floor. These teachers worked tirelessly to advocate for the children's education during their hospital stays. I saw through their constant dedication that it was not a simple task to keep a child educated in a hospital environment. As I delved deeper into their work, they highlighted the glaring gaps in success when transitioning a child from the hospital, back into their school. Ever since working with these teachers I have been unable to forget about this gap in communication that exists in the transition for children with special healthcare needs. I am dedicated to finding a solution for this chaotic and currently unacceptable system to aid in the success of a child's transition.

My experience in Study Abroad was equally influential to my growing interest in children with disabilities and healthcare needs populations. I spent my sophomore spring semester studying abroad in Dunedin, New Zealand. Not only did I experience the beauty of the country, but I was also involved in a mentoring program for adults with disabilities. This program gave me a new perspective on healthcare and disability rights in another country. This experience inspired me to dive deeper into my own countries disability healthcare rights, and find a solution for one of the largest issues that plague children with special healthcare needs. I was also given the opportunity to work in a school setting as a teacher assistant, full time for eight weeks. This experience was instrumental in enlightening me on how a variety of school systems work around the world, and how to properly advocate for all children's education. I participated in a teacher rally alongside the other teachers at my school and was able to stand in support of proper education for the children in New Zealand and all over the world.

Part III: Plan for Intellectual Inquiry

In order to fully understand the breadth of the hospital education system, I will explore the key individuals who aid in the success of this system. Through interviews, conferences, and continued course work, I will explore the potential gaps in communication between hospitals and schools, and the lack of accessibility for a child when they enter this transition. Although this problem exists all over the United States, in order to narrow my research, I will mainly focus my studies on the North Carolina school and hospital systems. These systems include the UNC hospital school and Duke Hospital school. These specific programs will be an excellent resource to me, as they combine a healthcare and teaching system in one location.

As I delve deeper into my research of support for children with special healthcare needs, I will use the transformational leadership theory to guide my proposed solutions. Transformational leadership, at its core, is the process of a leader and their team identifying needed change to create a vision in order to implement this change (Bass, 2006, pg. 4). This theory aligns with my proposed research. In order for children to be sufficiently supported in a hospital and school setting, they need a team of inspired individuals who will work together in an effort to help children to succeed. Transformational leadership does just that. By facilitating a team of individuals that will reinforce each other's roles in supporting children with special healthcare needs, a solution may begin to evolve (Giroux et.al, 2016). The improvement in the hospital to school transition will advance when a central position is created to facilitate all communication between key players. I will evaluate this form of leadership through interviews and through my own classwork as I study special education. Communication and team collaboration is an overarching theme of special education in general, and this theme will align with my proposed research. I plan to implement a research symposium at Elon University in the Fall of 2020 to highlight the importance of supporting children with special healthcare needs in the school system. I will discuss my research with undergraduate education majors who will benefit from this knowledge. I plan to extend this and reach out to local teachers and administrators who are in need of resources for supporting their students when they transition from the hospital back into their classrooms. If parents of these children need a safe place to discuss support and resources for their children, I will create an open forum with individuals I have interviewed from the community who will support these parents as their children transition back into the schools. By connecting the community together, I will work to create a positive environment for all individuals supporting children in their transition from hospital to school. I hope to gain experience as a leader through the opportunity to connect parents, teachers, and professionals. My experience studying abroad and immersing in the education styles of New Zealand will also provide a strong basis for understanding how children can benefit from support when transitioning back into the school system. I look forward to connecting my research with my undergraduate studies on a daily basis.

The individual interviews will be of great value to my undergraduate research. It is essential to hear from a variety of individuals involved in the hospital and school systems in order to truly understand the extent of the problem. I hope to initiate interviews with healthcare professionals, teachers, school nurses, parents, social workers, hospital school staff, and therapists that interact with children with healthcare needs on a daily basis. By discussing with them, the current gaps in success when a child transitions back into the school system, I will be able to pinpoint the key improvements needed to begin to answer my research question. I will ask questions about each interviewee's experience in working with children with healthcare needs, as well as more in-depth questions on how the hospital to school transition can be enhanced. I hope to conduct at least thirty, in-person or over-the-phone interviews during my time as a Leadership prize winner if I am granted the opportunity to do so.

I will focus my research on two main populations, to begin with. From my initial research, I have found that school nurses play a large role in supporting children with unique healthcare needs. Traditionally, care for CSHCN in the school falls on the school nurse (Heller et.al, 2004). But when a nurse is not supplied by a school, teachers, and staff must care for both the student's academic and medical needs (Kruger et.al, 2009). This often puts the student at risk of receiving less than adequate medical care (Knauer, 2015). It is also the nurse's responsibility to make sure that administrators, teachers, and any additional personnel who provide services to the student are knowledgeable on both the care needed for the CSHCN as well as the laws that surround this care (McClanahan et.al, 2015). I plan to interview school and hospital nurses in the North Carolina area to learn more about their essential role in caring for CSHCN.

The other population that plays an essential role in advocating for a child with special healthcare needs are the parents and caregivers of these children. Most parents of CSHCN have specific goals and hopes in mind when it comes to their child's education (Anderon, 2009). Parents often express frustration around teachers underestimating their child's abilities. At the same time, many parents feel that their child will benefit greatly from being in a school environment (Rehm, 2002. b). There are many reasons why a school setting is more beneficial for CSHCN compared to a home or hospital environment. These include the benefits of peer relationships, challenging and on grade-level academic work, and extracurricular and special activities (Shaw & McCabe, 2008). Students gain immense improvement in social skills and academic skills when they are able to interact with their peers in and outside of school. A parent of a CSHCN must constantly work to advocate for their child's needs. Their job can be supported with the help and communication of the hospital and school staff. I hope to interview a sample of parents to hear about their experiences in supporting their children as they transition from the hospital setting to the school setting.

There are a few essential organizations that focus on care for children with healthcare needs. The experts involved in these organizations will bring a new perspective to my research. The first conference in which I hope to present, is the Hospital Education and Academic Liaison Program

Conference (HEAL), taking place in Dallas Texas on April 15th, 2020. An opportunity such as this would be invaluable in expanding my knowledge on hospital and school systems as well as offering an opportunity to present my initial findings. Along with HEAL, I hope to present at the Council for Exceptional Children conference on February 10th, 2021 in Baltimore, Maryland. The Council for Exceptional Children Conference looks for presenters who are experts in advocating for children with disabilities and exceptionalities. I would hope to bring a new perspective to hospital education and how to support children in their transition back into the school system. Conferences are a crucial part of my learning experience as an undergraduate researcher as they will provide me with the opportunity to interface with individuals who have extensive experience in the hospital and education systems. I hope to gain insight from their practice and expand my understanding of support for children with healthcare needs. If I were to be rewarded with the Leadership Prize, I would value the opportunity to attend and speak at conferences such as these.

This summer I hope to engage in an internship that applies to my research studies. I have reached out to various disability advocacy organizations and special education legislation institutions in order to broaden my knowledge of support services available for individuals with disabilities and healthcare needs. This experience will be invaluable in expanding my knowledge base pertaining to my research and will aid me in proposing realistic solutions.

Part IV: Feasibility, Budget, and Timeline

Feasibility statement:

The underserved population of children with special healthcare needs would benefit significantly from an advocate. Individuals dedicated to the support and aid of children with healthcare needs would greatly benefit this cause. My research evaluating the most successful ways to aid in a child's transition from hospital to school setting would fit seamlessly into the three-semester long process that the Leadership Prize provides. The timeline provided below is a detailed tentative plan for positively impacting the lives and systems in place. Through the knowledge and support of the hospital and school staff, a successful solution will be implemented at the end of the three-semester time span. I am confident that this research will have a feasible and realistic outcome in order to truly make a difference.

I have reached out to various hospital and school staff to investigate initial interest in my research topic. I have received astounding positive feedback, with many individuals thanking me for the research I plan to begin. I hope that with this initial research, I can create a formal position of communication database that may continue to be used to aid in a child's transition from hospital to school. I have seen success in Chicago with the implementation of a home-hospital coordinator employed by the public school system. I believe that a system similar to this should be created in local schools and all over the country, in order to create one

individual who will work as a liaison between the hospital and the school systems. There is a realistic solution to the problem of inadequate support during hospital to school transitions, but action must be taken to aid in its success (Poursanidou et.al, 2008). Teaching Fellows provides us with an opportunity to pursue small scale research as an undergraduate student, and this opportunity has helped me to create a feasible and impactful research idea. Through the Leadership Prize, I hope to greatly expand this idea and be able to make a truly positive impact on children with healthcare needs and disabilities.

The funds provided by the Leadership Prize will provide me the opportunity to research, learn, and act on the hospital education system. Through the opportunity to attend conferences and intern with a disability organization, I will gain much-needed expertise in how the population of CSHCN will be supported in their transition back to school. The interviews I will conduct will provide an invaluable wealth of knowledge on the current systems in place, and what experts on this topic believe will be successful solutions. The funds provided by this prize will benefit children with special healthcare needs firsthand.

The proposed timeline listed below outlines the various learning opportunities I hope to experience through the Leadership Prize. By attending conferences, I will benefit from the knowledge of experts all in one place. I will have the opportunity to present my own findings and shed a light on the underserved population of children with special healthcare needs as they transition back into school. I will go through a series of interviews and analysis in order to divulge a proposed implementation plan. I will create an environment of discussion and support for parents and teachers who work to support children with special healthcare needs. I will also have the opportunity to present my findings to my own Elon community at SURF 2020 and 2021. This timeline, although tentative will allow me to fully execute my research to the best of my abilities and devise a thorough and accurate solution for my research topic.

Budget:

Data Collection	Total: \$350
Professional audio equipment	\$50
Transcription services	\$300
Interview Travel Expenses	Total: \$200
Gas money for interviews	\$200

Research Symposium	\$350
Materials	\$100
Catering	\$250
Conferences and Training Programs	Total: \$2,800
Attend Hospital education and Academic Liaison Program Conference - Dallas, TX (April 15-17, 2020) <ul style="list-style-type: none"> ● Flight: \$300 ● Hotel (2 nights): \$300 ● Conference registration: \$200 ● Food: \$200 	\$1,000
Present at the Council for Exceptional Children - Baltimore, MD (Feb 10-15, 2021) <ul style="list-style-type: none"> ● Flight: \$200 ● Hotel (2 nights): \$300 ● Conference registration: \$200 ● Food: \$200 	\$900
Attend Hospital education and Academic Liaison Program Conference - Location TBD (April 2021) <ul style="list-style-type: none"> ● Flight: \$200 ● Hotel (2 nights): \$300 ● Conference registration: \$200 ● Food: \$200 	\$900
Summer Internship	Total: \$1,000
Tuition for Over-time Research Hours	Total: \$2,500

Additional Funds used for community solutions and advocacy for children with healthcare needs	Total: \$300
Grand Total:	\$7,500

Timeline:

Fall 2019	Complete proposal, begin data collection, complete IRB, Literature Review, Collect potential interview candidates contact info, identify hospital schools of interest
January 2020	Winter Term: Trip to Washington D.C. with the Teaching Fellows to study Educational Policy
February 2020 - March 2020	Begin collection of interviews with teachers, school nurses, healthcare professionals, parents, hospital school staff, social workers, therapists
April 2020	Present at SURF for Teaching Fellows research component Present at Hospital Education and Academic Liaison Program Conference in Dallas, TX
May 2020	In-depth observation at a hospital school for multiple days to observe how daily hospital education processes work
Summer 2020	Intern with a disability organization
September 2020	Complete interviews
October 2020	Data analysis, qualitative data analysis looking for key themes and outcomes that will shape my recommendations
November 2020	Second round of interviews with questions

	altered after conclusion from data analysis Research symposium with Elon education students Community support meeting for parents and teachers of children with special healthcare needs
December 2020	Data analysis, qualitative data analysis looking for key themes and outcomes that will shape my recommendations
January 2021	Write up final report, teaching special education practicum begins
February 2021	Present at the Council for Exceptional Children Conference Feb 10-15, Baltimore, MD
March 2021	Present at Hospital Education and Academic Liaison Program Conference
April 2021	Present Leadership Prize completed at SURF
May 2021	Graduate

Part V: List of sources

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