SCHOOLSICK:

Educational Support for Children with Chronic Diseases in Nashville, Tennessee

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theWONDRY

A LINGERING MEMORY

I am Ai (Jasmine). In the summer of 2019, as a new volunteer aiming to help low-income families, I got to know Yu as an online tutor. By the time, Yu was a fourth grader recovering from Leukemia. Yu was a happy child who loved to share his new Ultraman cards and funny jokes, but sometimes he looked upset.

ONE DAY DURING A TUTORING SESSION...

What's wrong today? Is the math too hard for you?

It's just...I don't know.

If you want, we can chat for a minute.

I miss my friend...

Yeah, I know it must be very hard not being able to go to school.

No, I am used to this, but he passed away.

Who passed away? Your friend?

The boy next to me when I was in the hospital room.

Oh...I am so sorry to hear that...

It's ok, don't worry. What page are we on?

With a gentle smile, Yu nudged me to go on with the lesson. I didn't know how to respond for I was shocked by how much these children with chronic diseases might have to go through.

A year later, because of the rules of my organization and a volunteer shortage, I was then assigned to teach a new child with more urgent needs. Consequently, I needed to end the lessons with Yu. It was a hard farewell for both of us, and Yu's family...

THE LAST CONVERSATION WITH YU'S MOTHER

Do you have to end the tutoring?

Yes, unfortunately. The service time is a year.

But I don't think Yu is ready. He will be left behind in school!

I have tried my best to help him within the year. I can still answer questions for him.

Can you keep teaching him? Please! He likes you a lot.

Sorry, I can't. I am still in school, so I can only teach one child at a time.

Is it because we don't give you money? I can pay you!

It's not like that...

You know we can't afford much... but I can try.

Yu's mother thought I ended the lessons because of money. Again, I didn't know how to respond. It is hard to tell a mom that I need to prioritize another child and my own school work.

I knew I was helping these children with chronic diseases and their families, but it was not enough. Therefore, I have been learning, thinking, and convening more people to join and become the lights for these children.

This paper is dedicated to all the young warriors fighting against diseases and the kind souls who love to help.

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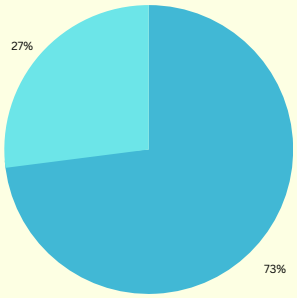
INTRODUCTION

Children with chronic diseases have **different growth and educational experiences** from their peers (Boles, 2017). For medical reasons, they usually have to leave their school and stay in the hospital for a period of time. Consequently, chronically ill hospitalized children cannot receive instruction from their old school setting and are forced to move between their immediate environments. However, **a lack of attention** and **support in educational resources** is posing an underestimated challenge to their education and mental well-being (Boles et al., 2017).

In this paper, we analyze the challenge from a broader ecosystem by applying system thinking models. Combining our literature review and semi-structured interviews, we propose an iterative two-step model-creating and demonstrating social revenue-for possible transformation in the services provided by school districts, healthcare, research, and mission-driven organizations.

*__Social Revenue__: We defined social revenue as the quantified value of the social value of the social programs or the services provided.



27% **of children have a chronic health condition**

1 in 15 **children have multiple chronic health conditions**

10-20 **weeks of school missed a year due to leukemia**

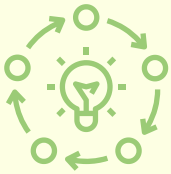
POSITIONALITY & PARTNERSHIP

As international students from China, we all have previous experiences with children with disabilities in Chinese educational settings. Jasmine has been working with five to six chronically ill children for nearly four years as a tutor, and program administrator in an online tutoring NGO. This project was initially conceived to do a comparative analysis of the US vs. China in the educational setting. However, after preliminary scoping, the team of three members was assembled, and the scope changed from a comparison to a needs gap assessment of the local system itself and proposing solutions to address those gaps. We based our project on Nashville because of its geographic proximity to our university, its educational history, and the diversity in the school-age population. Our experiences with the Chinese educational system and its population give us a unique perspective when looking at a fundamentally different system here in the US.

RESEARCH METHOD

Literature Analysis: We meticulously examined **70+ sources**, including research articles, community reports, and news sources.

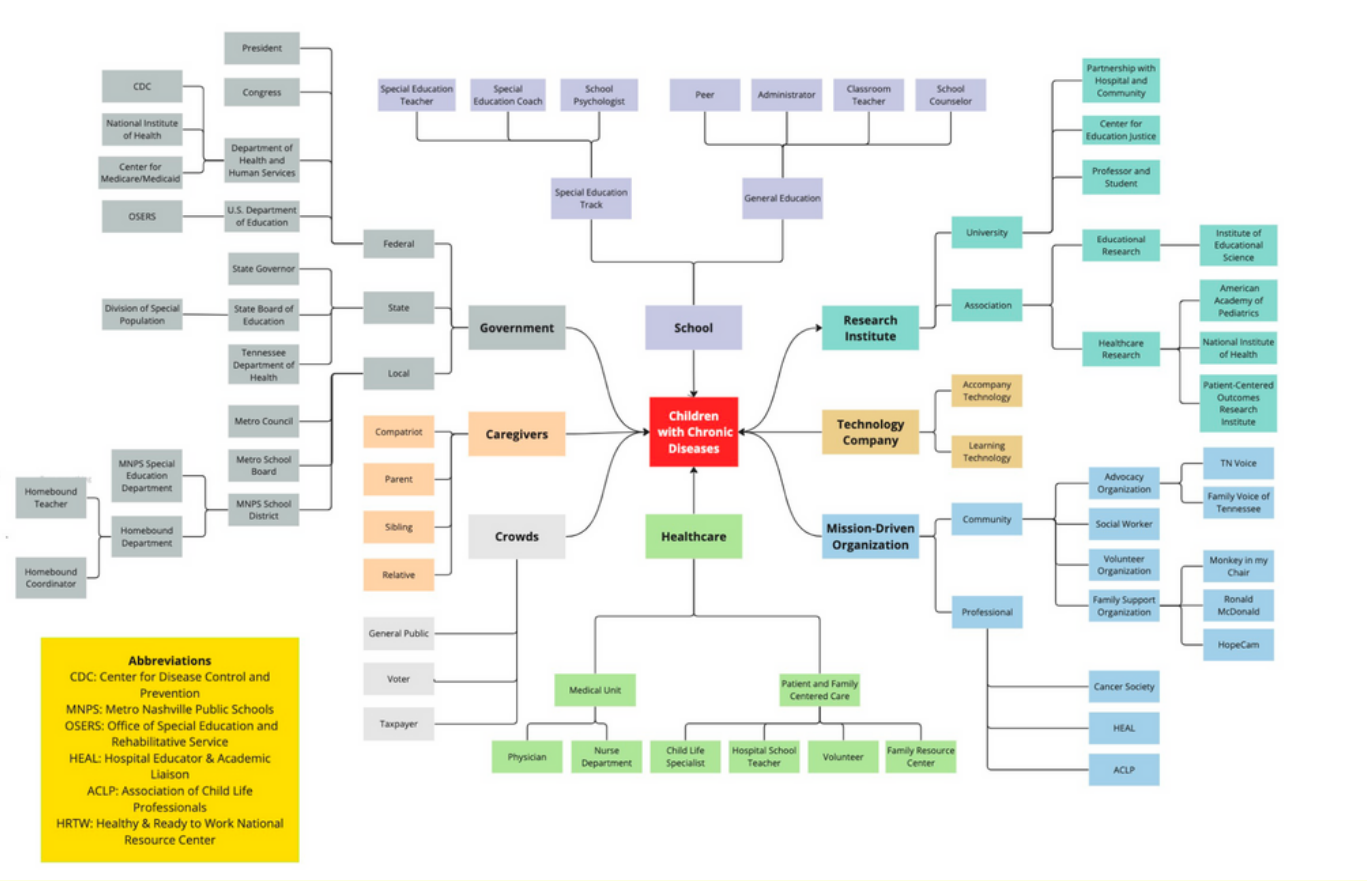
Semi-Structured Interviews: Our group conducted **21 interviews** (in-person or virtual) with experts and stakeholders from different fields, including a child life specialist, a special education coach, and a senior-level hospital patient and family-centered care director.



System Thinking: Utilizing **systematic and bottom-up thinking**, we mapped out the relationship among different interest groups and how they collectively shape the system.

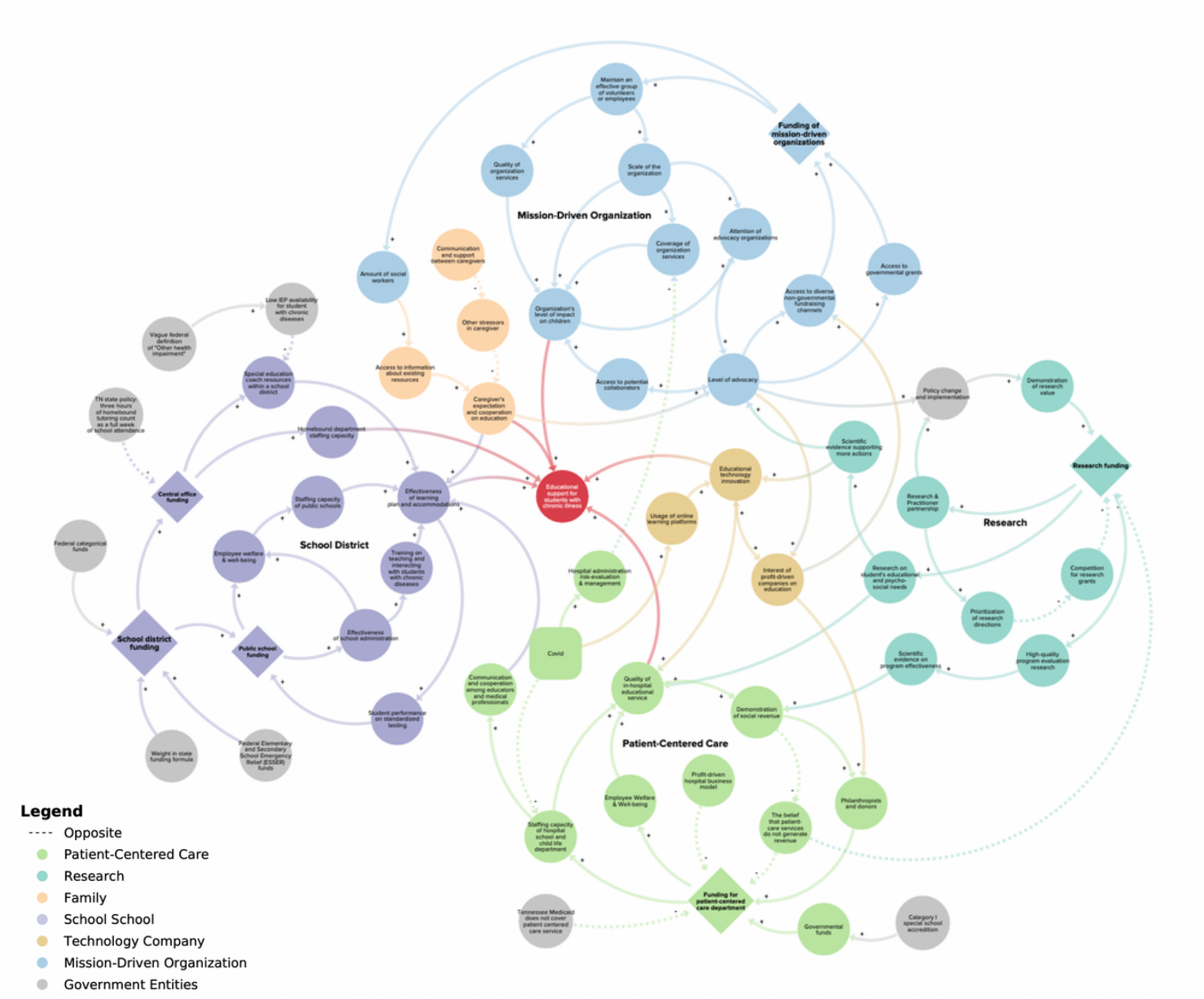
***Acknowledgement**: As undergraduate students, we have limited experience with children with chronic diseases. **To bridge this gap, we have made a concerted effort to gather insights from various experts who work directly with these children and assess their needs objectively.** Additionally, we focused specifically on support provided to children in public schools where students are less likely to afford private tutoring outside of school (Islam et al., 2021).

STAKEHOLDER MAP



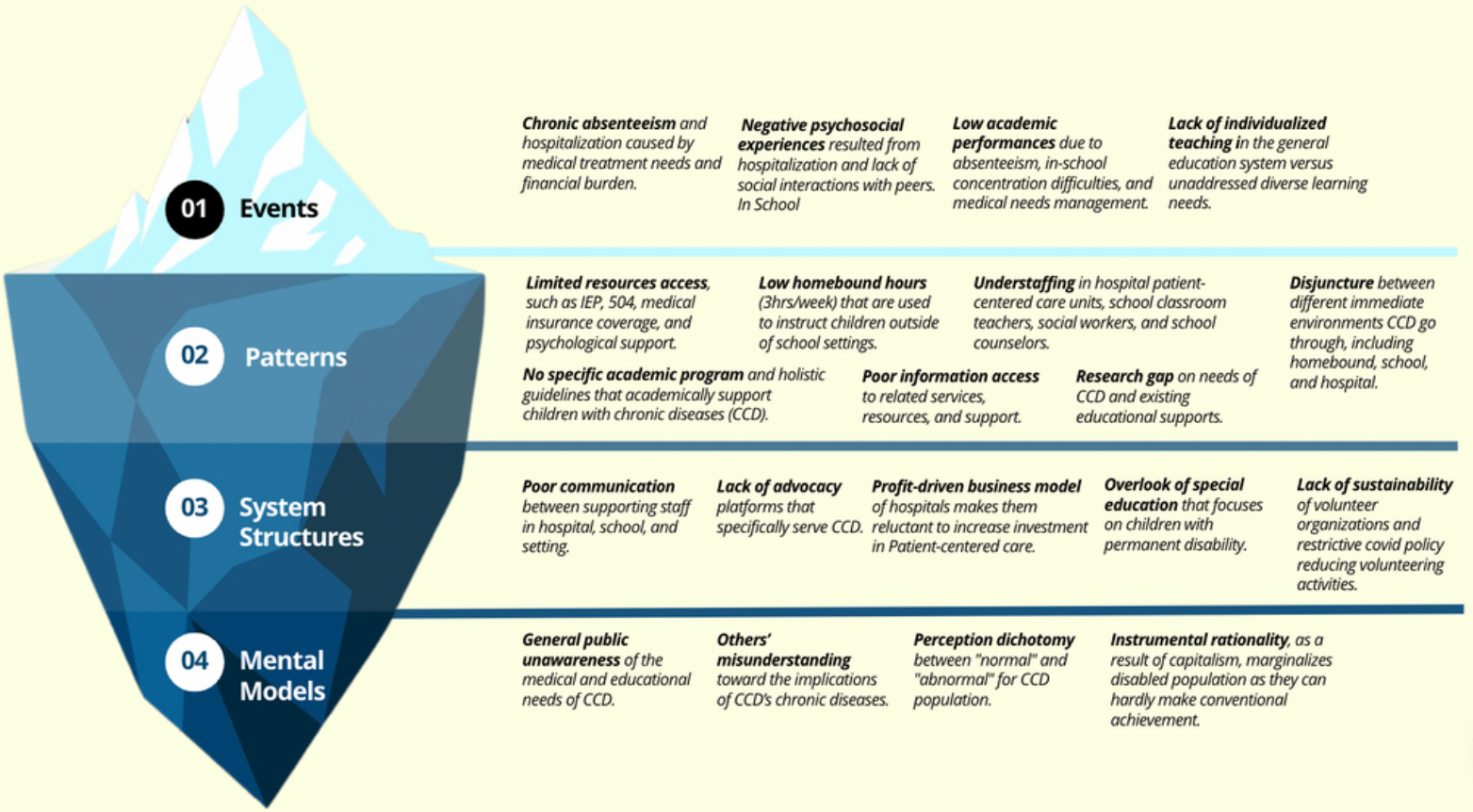
We identified **key stakeholders in eight fields**: governments, schools, research institutes, technology companies, mission-driven organizations, healthcare, crowds, and caregivers.

SYSTEM MAP



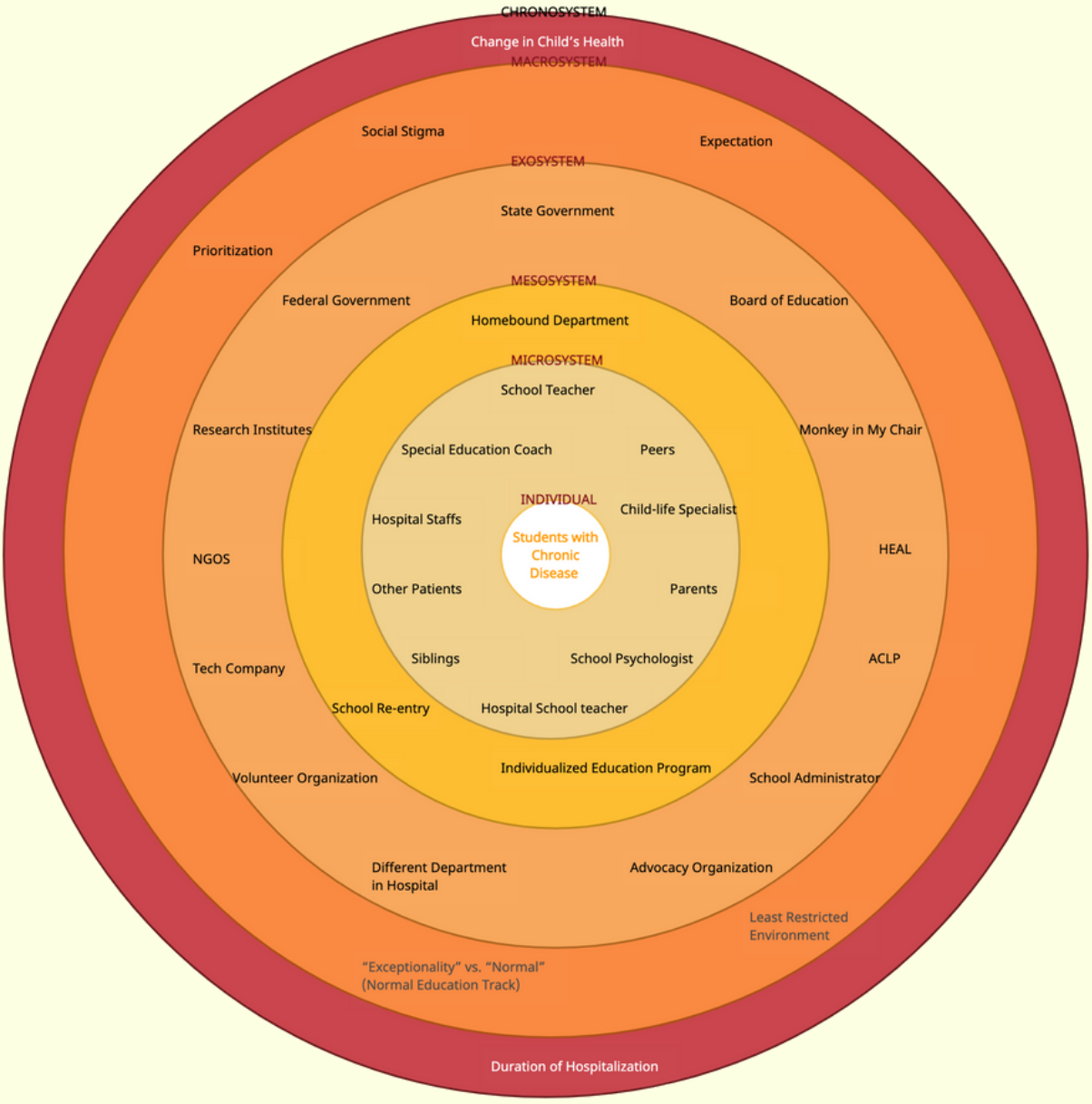
We examined subsystems that are involved in the challenge and mapped the intra-relationship between **elements of subsystems and the inter-relationship between them**.

ICEBERG MODEL



We used the Iceberg model to dig the system structures and mental models that undergird events.

PERPETUATING FACTORS



Bronfenbrennner Ecological Model

Bronfenbrenner's map organized the context of development for students with chronic diseases. **The outer layer it is in the map, the less directly it interacts with the students but also the larger systemic power it has.** On the macrosystem level, we identified four **perpetuating factors** as follows.

SOCIAL STIGMA

Children with chronic illnesses typically have **more absences from school** due to their medical needs, which results in a detachment from their peers and classes. After school re-entry, children usually suffer from **a decline in academic performance**, and some students are **retained for a grade** (Crosnoe et al., 2023). This results in a strike to the **self-esteem** and **self-confidence** of students as they struggle to keep up with their peers or are surrounded by classmates all younger than themselves (Koike et al., 2017). Certain chronic illnesses may also lead to **misconceptions** and **stereotypes** about children after school re-entry because of their special needs (Nunes et al., 2022). The change in appearance caused by medical procedures may further cause the alienation of these children and exacerbate their low self-esteem.

EXPECTATION

Research has shown that students who struggle with chronic diseases are more likely to experience academic difficulties (Thies & McAllister, 2001). As a result, teachers often have **lower expectations** for these students when it comes to their academic performance. According to a study by Gershenson, Holt, and Papageorge (2016), teachers may hold lower expectations for students with chronic illnesses because they believe these students are less likely to succeed academically. Unfortunately, this can lead to **a decrease in the amount of attention and support** these children receive in school. Additionally, teachers' low expectations can contribute to the students' **lack of motivation and feelings of fatigue toward education**, which further reinforces the belief that they cannot succeed academically (Rubie-Davies, 2007; Walkey, McClure, Meyer, & Weir, 2013).

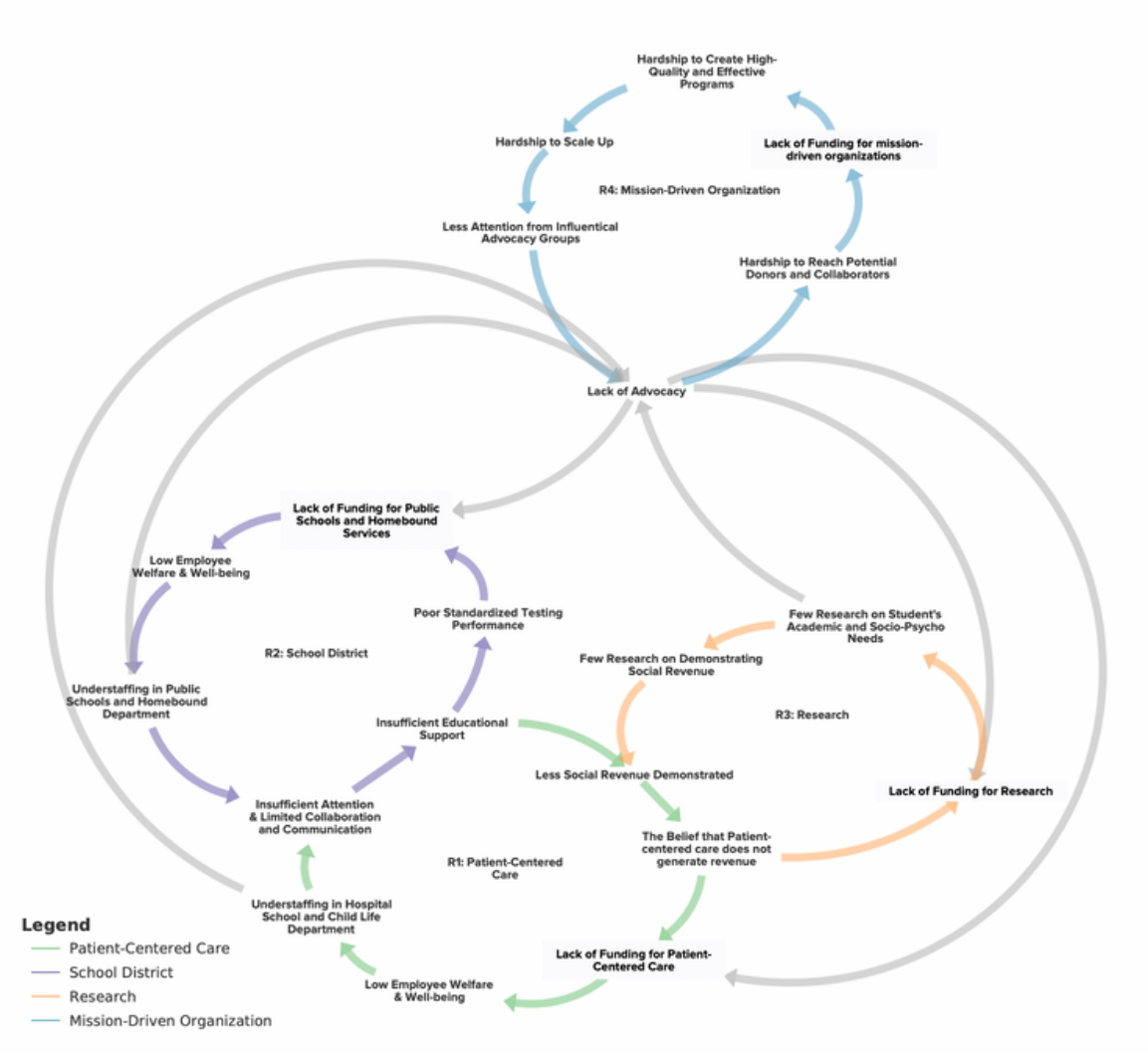
PRIORITIZATION

The current education system fails to prioritize the specific needs and challenges of children with chronic illnesses. As a result, there is **a lack of attention and resources** devoted to addressing their individualized needs, including **limited accessibility** to accommodations, specialized learning plans, or social workers who can provide support for their learning and overall well-being. What's more, according to Anderson and Davis (2011), despite the growing number of chronically ill children in the United States, there is a lack of research on educational support for these children. This lack of prioritization results in **restricted opportunities** for these children to keep up with their schoolwork and reach their full potential for academic success (Wagner, Austin, & Von Korff, 1996).

NORMALITY MENTAL MODEL

One type of education alone can hardly fulfill the diverse needs of all students. Particularly children grappling with chronic diseases possess special requirements that differ from traditional educational practices. They need **a tailored approach** to prioritize their psychological well-being, social connections, and their overall happiness. In the education system, the "normal" track typically refers to the standardized and traditional sequence of courses and aspirations that students follow to achieve the ultimate goal of graduation from one stage to the next (Azoulay & Starr, 2019; Gamoran & Mare, 1989). However, **societal pressure** to conform to this norm can negatively impact the mental health and well-being of individuals who deviate from it (Lorenz et al., 2011). This pressure can be particularly harmful to children with chronic illnesses as it may push them towards the "normal" track instead of a more individualized educational approach that better meets their needs.

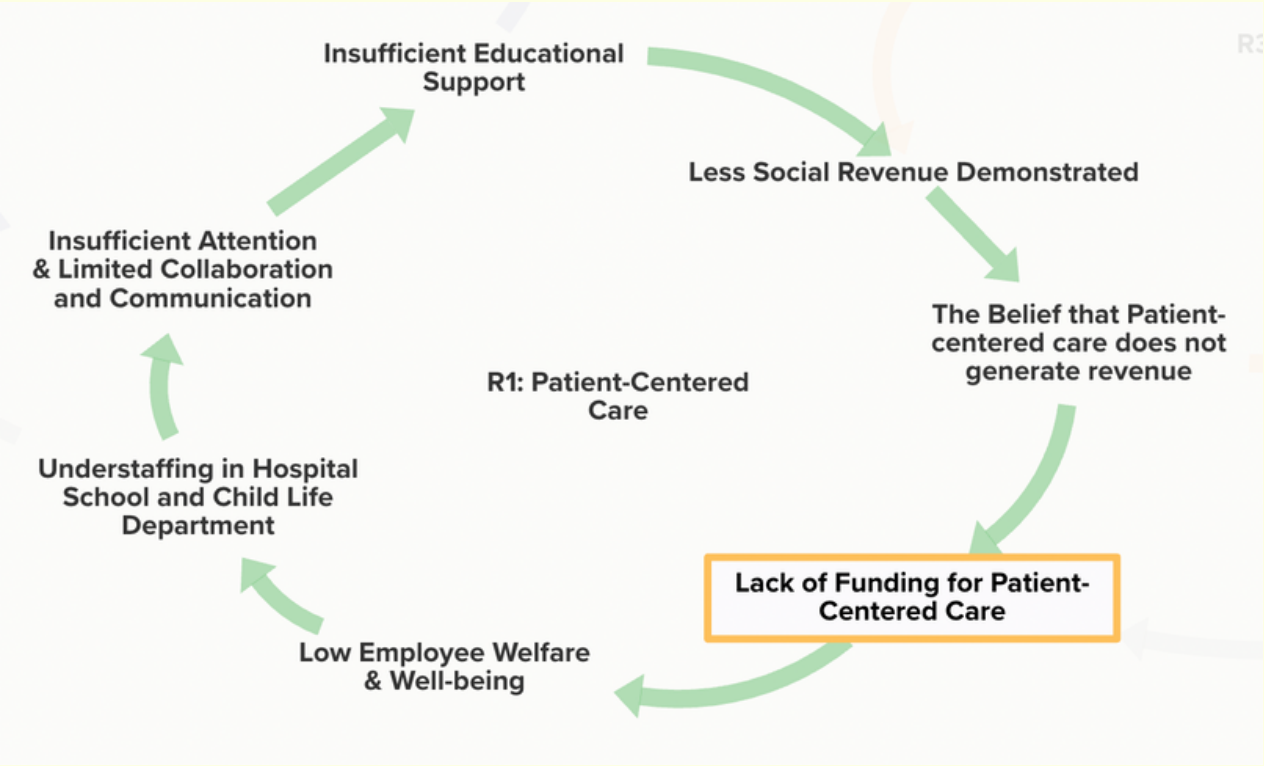
ROOT CAUSE: FUNDING SHORTAGE



We identify a **lack of funding** as the root cause of insufficient educational support for children with chronic diseases. Funding shortage is reflected at three levels: **amount**–total monetary capital, **access**–eligibility for funds, and **allocation**–distribution of funds with priority agenda.

Specifically, funding shortage is the **root cause**, with **negatively reinforcing causal loops** in four subsystems: patient-centered care, school districts, educational research, and mission-driven organizations. **Interlocking with each other, four causal loops form a large systemic vicious circle that reinforces the funding shortage status quo.**

CAUSAL LOOP 1: PATIENT-CENTERED CARE



The funding of patient-centered care comes from the hospital's budget and donations, yet this amount is limited, due to Tennessee Medicaid providing only medical support as well as the hospital's **profit-driven business model**.

"The hospital administrators **prioritize revenue-generating departments** over those that generate less profit. This causes a limited amount of **top-down funding** for patient-centered care." - Child Life Specialist

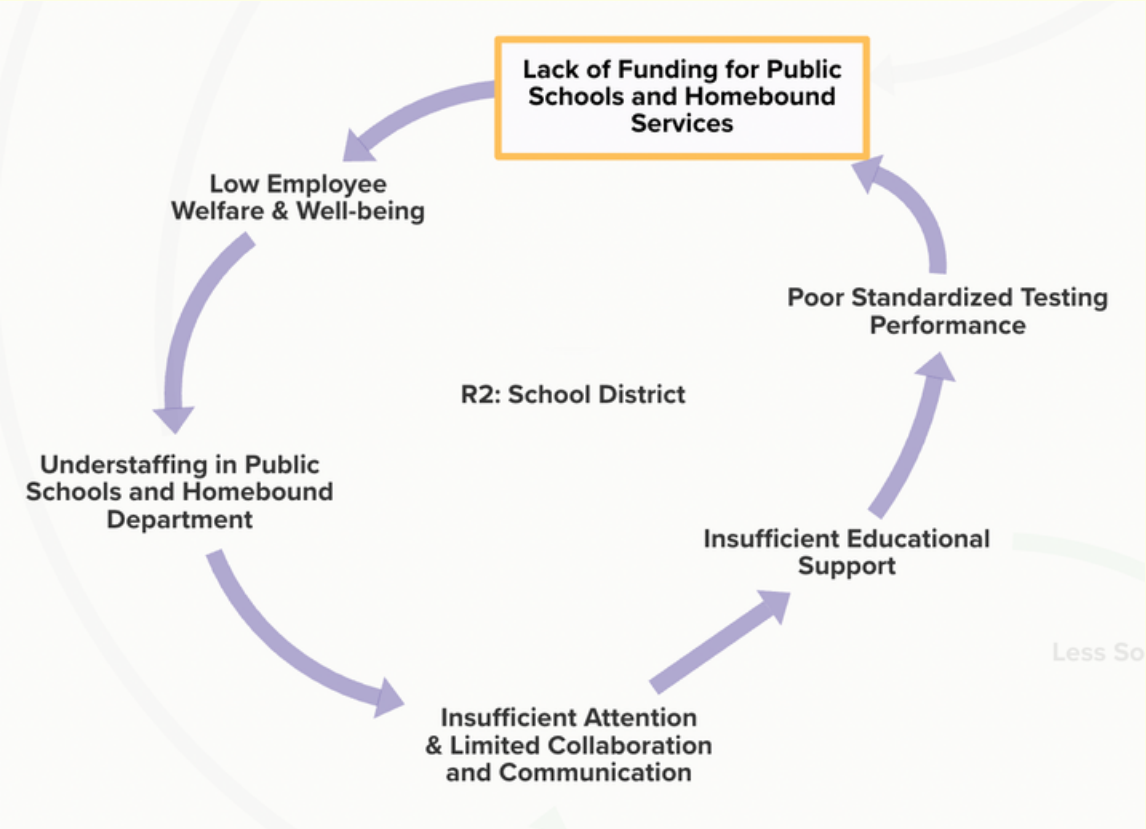
The operation of the patient-centered care department is also highly dependent on philanthropic donations.

"Donation is **not a stable source** of funding. We use advertisements to display our programs and attract donors, but the amount of donation still depends on **donors' perception of the value of such services**."
– Director of Patient & Family Centered Care Department

Furthermore, difficulty obtaining special school accreditation for the hospital school prevents access to governmental funds.

Underfunded hospital schools and child life departments have **low staffing capacity**, leading to **poor-quality educational services**. This, in turn, negatively impacts student academic performance and psychosocial well-being, making it **difficult to secure funding** from the hospital or outside donors.

CAUSAL LOOP 2: SCHOOL DISTRICTS



School districts in Nashville receive funding from the federal, state, and local governments. Half of the district funds are general funds that go to public schools for their daily operation, and a quarter of it flows to the central office to which the homebound department and the special education department belong (Metro Nashville Public Schools, 2023).

Tennessee allocates 35% of its state funds to education, which is slightly below the national average of 38% (National Center for Education Statistics, 2022). Furthermore, **94 out of 95** school districts in Tennessee are **dependent districts** that are regulated by the local government.

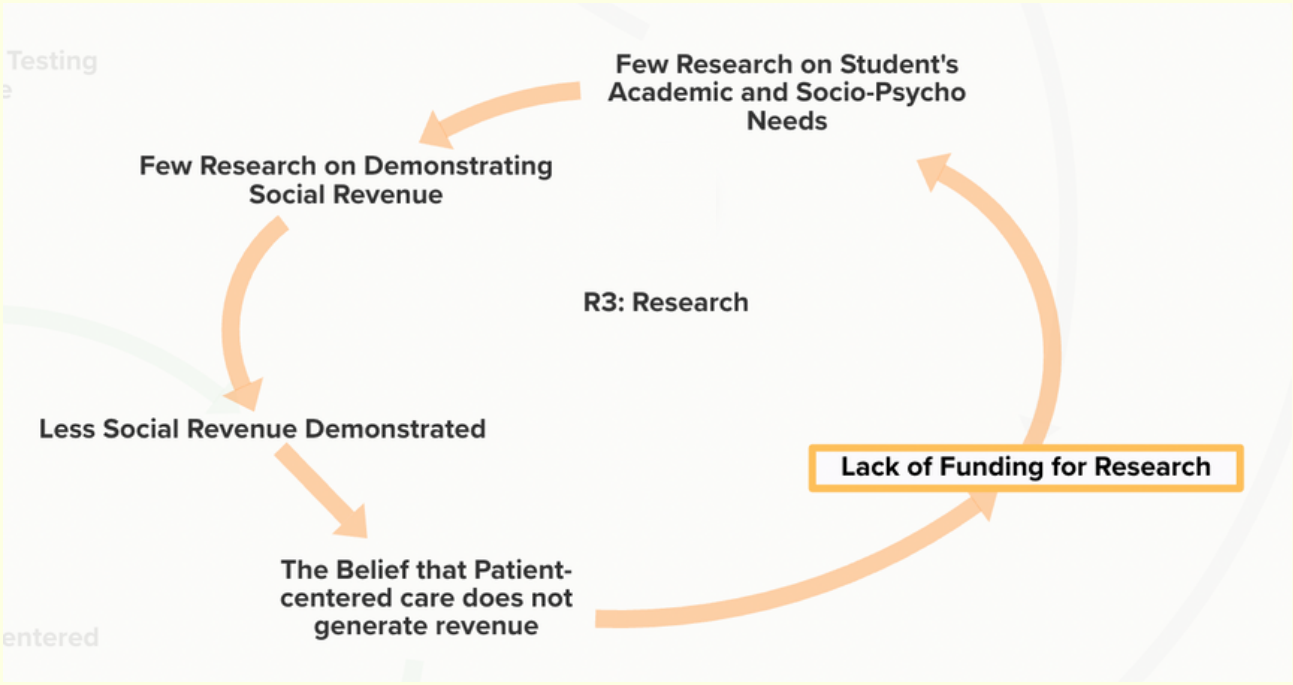
"Dependent school districts have **less influence** on local taxpayers and their votes, so they are **passive players** in the game of fundraising."
- Professor of Public Policy and Education

The funding shortage of public schools causes **low staffing capacity** and **less effective school administration**, which are essential to the quality of educational support. Further, insufficient educational support leads to **lower student performance** on standardized tests, resulting in **a reduction of funding** for the school (Neymotin, 2010).

Underfunding of the central office leads to **limited homebound and special education resources**, contributing to insufficient educational support for children with chronic diseases.

"I would like to have another full-time SPED homebound teacher added to our team. Currently, there are **just 2 of us** who are full-time, so I do have to find teachers who are interested in earning extra money by **doing hourly homebound** after they finish their school day."
- Homebound Teacher

CAUSAL LOOP 3: EDUCATIONAL RESEARCH



The majority of the educational research (53% in 2018) is funded federally by the Institute of Educational Science (Institute of Education Sciences, n.d.). Although the funding for the federal education department has increased historically, the research funding for education keeps **decreasing in proportions** within the last decade (National Center for Education Statistics, 2021).

"The research funding is **not sufficient** at all. So many good and important proposals are turned down, a **discrepancy** between the supply and demand."
- Director of Tennessee Education Research Alliance (TERA)

The issue is self-perpetuating—the existing research on education makes a **limited practical impact**, making governmental entities **reluctant to fund**.

"The main reason is what we call the **research-practice divide**. In the past, researchers and policymakers rarely interacted with each other. Maybe a policymaker took a few glimpses out of interest. That's all. When the research does not **translate to decisions** made on the ground, the federal government does not see a reason to increase funding."
- Professor of Political Science

Most funding goes to research that studies achievement outcomes, which produces objective data most directly related to policy decisions (Weiss et al., 2008). Therefore, less funding is allocated to research focusing on **student's psycho-social needs** and **relevant program evaluation**, even though such programs are crucial to chronically ill children's well-being (Meltzer et al., 2018)

CAUSAL LOOP 4: MISSION-DRIVEN ORGANIZATIONS

Mission-driven organizations face shortages of government funding and non-government fundraising.

"It is **hard to get both local and national grants**. Monkey in My Chair [a program connecting patient and school-aged peers through stuffed monkeys] gets funding from Kansas, but it is a national-wide program. The funding from Kansas can only be used in Kansas."
- Graduate Researcher on Monkey in My Chair

The lack of funding has a direct impact on the maintenance of an effective group of volunteers or employees, which **keeps the organization from scaling up and providing services with higher quality**. Further, the limited scale of organizations **restrains advocacy and their future development**.

"Small groups have **little voice**. Those large advocacy groups don't see them, so they won't provide help. If they can't scale up, they also have **trouble finding collaborators**, and they **lose their chance of increasing coverage and influence**."
– Professor of Human and Organizational Development and parent of chronically ill child

EXISTING SOLUTIONS

PATIENT-CENTERED CARE

EXISTING SOLUTIONS

- Patient and family-centered care services that **foster beneficial partnerships**.

DEFICIENCY

- **Limited scale** is not matched with its **high demand**.
- A need for improved **high-quality communication** within and between the hospital, school, and families.

SCHOOL DISTRICTS

EXISTING SOLUTIONS

- **Coordinated school health** is responsible for health education and provides school-based screenings and therapies (Tennessee Department of Education, 2021).
- There is a district-level **Homebound Department** that supports students who cannot physically attend school and provides academic instructions to children.
- In rare situations, children with chronic diseases can qualify for **Individualized Learning Plans (IEPs)**.

DEFICIENCY

- 18% of schools **do not meet** the loose of criteria 1:500 for certified counselors and students (Tennessee Department of Education, 2021).
- The requirement of providing a minimum of **3 hours** of instruction per week is **too low to provide equivalent classroom instruction** while homebound teachers are **understaffed** to go beyond it.
- Families of children who qualify for 504 and IEP are **not aware** of the services they can receive (Lutenbacher et al., 2012)

EDUCATIONAL RESEARCH

EXISTING SOLUTIONS

- Tennessee Education Research Alliance fosters **communication between policymakers and researchers** (Peabody College of Education and Human Development, n.d.).
- There is a wealth of **evidence-based empirical research** in hospital settings (David and Mari, 2015; Anderson et al., 2020).

DEFICIENCY

- The research **lacks cost-effectiveness and cost-benefit analysis** to identify the causality between the program and its expected outcomes
- There is a **lack** of an equivalent level of **evidence-based implementation** that can produce change.
- The **shadow prices** of social programs–values that are not reflected by market values– are **hard to capture** (Karoly, 2008).

MISSION-DRIVEN ORGANIZATIONS

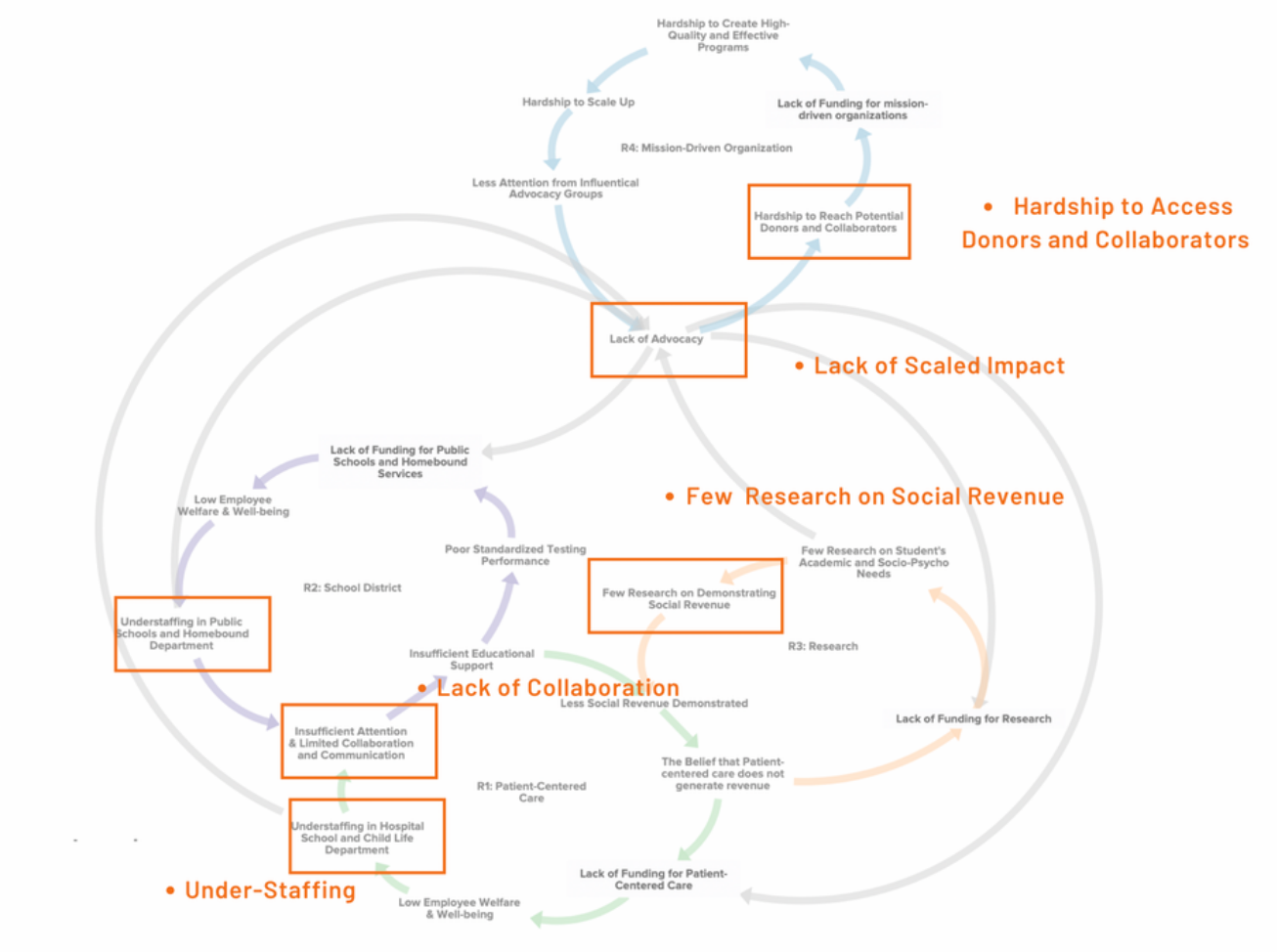
EXISTING SOLUTIONS

- Monkey in My Chair and Hopecam help students to connect with their peers and to help **overcome social isolation**.
- Ronald McDonald House provides free, home-like **accommodation** for outpatient children and their families
- Advocacy organizations such as Family Voice of Tennessee raise **public awareness** and influence **public opinion** on related issues

DEFICIENCY

- Organizations experience **difficulty scaling their influences** and attracting the public's appreciation
- Impacts of the programs are **strained by families' low income** and **high monetary & time costs** of caring for chronically ill children (Lutenbacher et al., 2012).
- Moreover, **few platforms** are spreading chronically ill children's **voices**, except for arthritis (Arthritis Foundation, n.d.).

GAPS IN THE SYSTEM

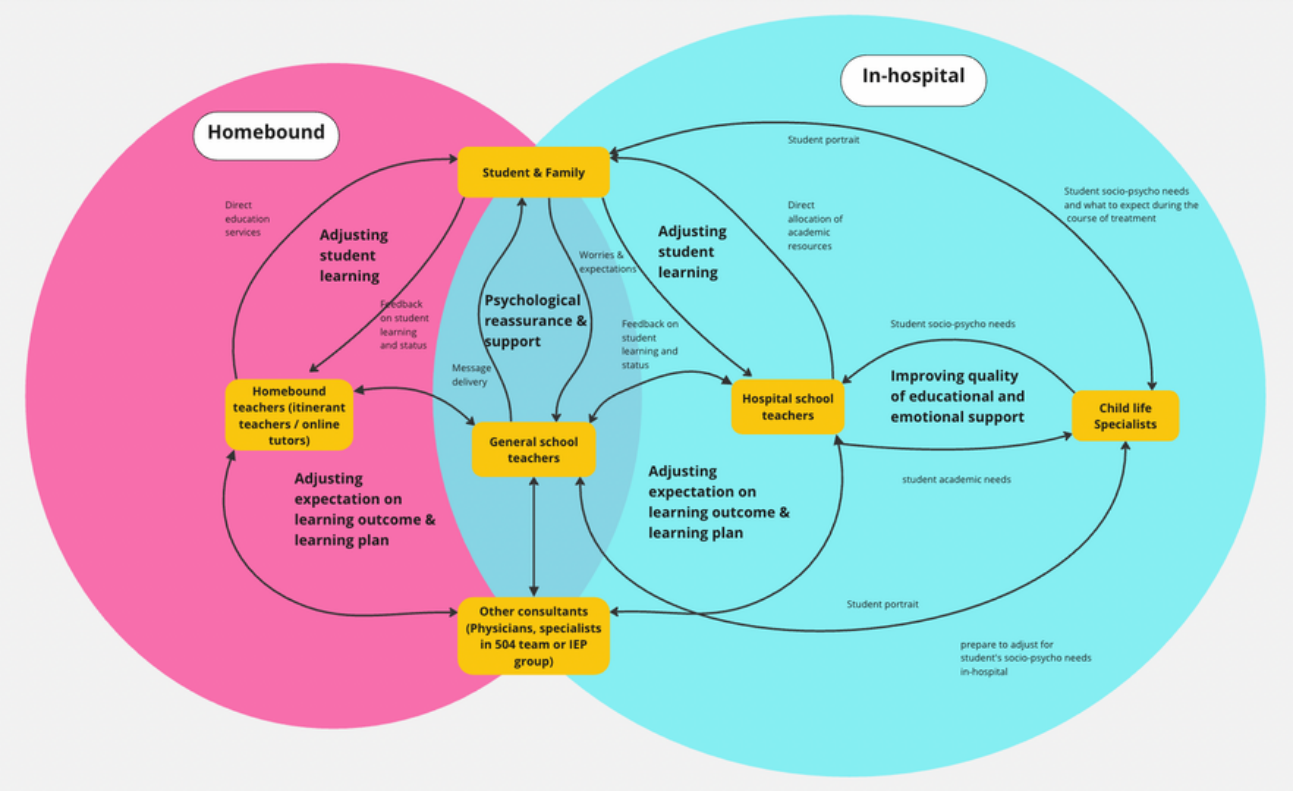


The deficiencies of existing interventions are due to the vicious circle of funding shortage. To **break** the interlocking causal loops of funding shortage, we considered root causes and existing interventions to identify five gaps, along with levers of change and interventions.

AREA OF FOCUS	GAP	LEVER	CHANGE
Patient-Centered Care	The **understaffing** of hospital school teacher and child life specialists	Inter-hospital collaboration and volunteer program	Hospital school teachers between different hospitals **fill the vacancy of each other's subject specialization** Build the **volunteer program** to address the understaffing issues to provide a more comprehensive education in various subjects that caters to each child's individual needs
School Districts	**Understaffing** of homebound teachers & school teachers and **lack of regular check-in**	Recognize administrator-teacher collaboration and school leadership programs	**Distribute more money** to school leaders' discretion to **make localized decisions** to address chronically ill children's needs, such as changing health education priorities, and build sustainable partnerships with third-party organizations, like volunteer groups **Set evaluation and supervision standards** for homebound services to secure students' educational support and channel communication between homebound teachers and hospital school teachers **Create leadership programs that empower** school administration without adding more staff
MIssion-Driven Organizations	Difficulties to reach **sufficient numbers** of donors and collaborators	Recognize the diverse fundraising strategies through community coalition	**Create a community coalition,** inspired by localized funding strategies of the TN Ronald McDonald House that collaborate with local enterprises to provide free meals, furniture, and repair services **Establish collaboration** and exchange of resources **between organizations** that share a similar mission

AREA OF FOCUS	GAP	LEVER	CHANGE
Advocacy	Lack of specific advocacy platforms with **influential children's voices**	Recognize positive youth experiences and school as a social center	Establish online **positive representations** of children with chronic diseases
			Advocacy Organizations **collaborate with schools to promote discourses** about knowledge of chronic diseases to address the stigma
			Collaborate with advocacy organizations **whose populations overlap** to create larger influences
Educational Research	Lack of research that **demonstrates social revenue** and suggests evidence-based interventions	Recognize inter-departmental collaboration, student work, and community engagement.	Establish **interdisciplinary collaboration** that leads to applied research
			Develop **community-university partnership** and reward research efforts
			In Nashville, there could be partnerships between applied research programs **in educational and medical contexts**, such as TERA and Evidence-Based Nursing Practices
			Encourage and incentivize **student initiatives** with the recognition of their equally valuable contribution

IDEAL COMMUNICATION MODEL



Our group designed a communication model to improve the education quality for hospitalized students. The model involves collaboration between hospital school teachers, general school teachers, homebound teachers, students with their families, child-life specialists, and other consultants. For instance, the hospital school teachers can collaborate with general school teachers, who keep them updated on the progress of students, while the hospital school teachers provide feedback on the students' learning in turn.

Overall, the proposed model aims to **improve the educational experience** and **create more social revenue** for hospitalized students by fostering effective communication and collaboration among all parties involved.

INSIGHTS & LESSONS LEARNED

As we all have worked as volunteers in the related program before, we came to the project with the preconception that increasing volunteer numbers would help address the issue. However, as we dived into the issue, we unveiled more unexpected problems. Although understaffing is one of the key issues, more gaps exist and hinder the system from operating effectively. In fact, the lurking defects behind the appearing issue of lack of educational support are much more **multifaceted** and **complicated** than we thought before.

As for our **personal takeaways**, we understand everyone plays a role in resolving the issue and carries shared responsibilities. In acknowledging the general public's lack of attention to this issue, we find that people often prioritize issues that directly impact them and disregard the struggles of others, particularly those in marginalized groups. We must connect to this caring for the education of chronically diseased children and make concerted efforts to help, **as we sincerely believe that all children have equal rights to receive a proper education**.

We sent invitations to each interviewee to watch our local presentations. To our surprise, Dr. Patti attended and sent us an email right after it, **"our children will be poised for improved outcomes if you continue with this work."** At that moment, we realized that we were not just doing a competition. There was an issue that few paid attention to, and we were making actual impacts by trying to understand it and solve it. Our interest transcends to the connection with these stakeholders.

Seeing ourselves as student scholars and the Map the System competition is the incubator for more student researchers like us. We know the importance and the value of our work: **the more we delve into a problem, the more we empathize, and the greater our impact becomes**. After Map the System, we will work with Healthcare Studio and have the support from medical champions to continue our projects, which **we genuinely hope will support the future educational resource for children** at Vanderbilt University Medical Center and potentially in other institutes as well.