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UNIVERSITY OF KENTUCKY
LEWIS HONORS COLLEGE

**Creating Change in Pediatric Health Disparities: Utilizing Systems-
Based Thinking to Overcome Disparities Affecting Pediatric Type 1
Diabetes in Kentucky**

by

Sydney Speed

AN UNDERGRADUATE THESIS SUBMITTED
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Abstract

Healthcare disparities are perpetuated and upheld for patients with type 1 diabetes (T1D) in rural and underserved urban areas of Kentucky. By adopting systems-based thinking, we can identify areas of the healthcare system to change to eliminate these disparities. Namely, key leverage points of this system include distribution and utilization of resources, finances and the movement of money, and communication pathways. To address the disparities surrounding pediatric T1D in Kentucky, a state-wide medical event called Kentucky Diabetes Family Day (KDFD) was hosted. The focus of this event was to lessen the effects of these specific healthcare disparities by altering key leverage points in the medical system. The goal of KDFD was to connect families and kids experiencing a T1D diagnosis in rural and underserved areas of Kentucky with pediatric healthcare resources and education. This successful and cost-effective event provided these resources for free and created change in 43 people's lives, while contributing to the fundamental change of the medical system serving people with T1D in Kentucky.

Motivation

When I was seven years old, I was diagnosed with type one diabetes (T1D) in a small town in Kentucky with limited healthcare resources. My first doctor told me that I would never play sports, have a family, or be a productive member of society because of my condition. Being a small child in a hospital, I believed these limitations. My family chose not to accept this prognosis and took me to a pediatric endocrinologist at a large, research-driven hospital where I learned that with management, I could do anything I wanted in life. Within the span of one week, I saw my entire life paradigm change twice.

Throughout my childhood, I experienced the isolation and social implications of being a kid with a chronic condition, and the lack of healthcare resources available in small-towns and rural areas. I was socially and medically isolated. Due to this, I began working with other kids with T1D. I have devoted most of my volunteer time and outreach to helping kids with T1D learn to manage their diabetes and live the lives they want to lead.

Upon moving to the University of Kentucky (UK), I began taking classes for Singletary Scholars. We focused on community service and understanding systems to fundamentally create change. We examined how systems are structured and how systems interact with society to create positive and negative changes. Our education focused on determining how systems function so that societal issues could be prevented by altering the systems that cause them, rather than be temporarily remedied by reacting to it.

Utilizing this education, I aspire to alter the systems in place that cause Kentucky children to be medically isolated from healthcare resources. I aim to use my Singletary education and the resources of the University of Kentucky and Lewis Honors College (LHC) to create the change I wish to see in our state. Thus, I created Kentucky Diabetes Family Day, an event dedicated to addressing a root cause of this medical disparity for many families: the lack of

medical education and opportunities to obtain resources. I also aim to create a model of systems thinking for addressing societal issues to empower other Singletary Scholars to create the change they wish to see in the future.

Introduction

In America, vulnerable populations in both urban and rural areas face complex healthcare disparities stemming from a variety of underlying causes. Kentucky, a state with a growing urban population and a large established rural population, is not exempt from these disparities. Such disparities originate from issues such as maldistribution of physicians and resources, prevalence of low socioeconomic status, communication breakdown between patients and providers, and a lack of sufficient political policy protecting those with T1D. To effectively consider and understand these disparities in Kentucky, we can characterize the complex interplay of underlying factors as a social system. Tseng and Seidman (2007) broadly describe social systems based on the social interactions that comprise them, as well as their corresponding resources and how these resources are allocated within the system. Meadow's further breaks down the system concepts into elements, interconnections, and purposes, which can be fundamentally altered to change the functioning of a system (Meadows and Wright, 2008). This systems-based thinking can be used to identify changeable aspects, or leverage points, of Kentucky's healthcare system that contribute to disparities. Specifically, it can be used to identify leverage points that contribute to disparities based in inequities in resource and physician distribution, socioeconomic status, and communication pathways.

Kentucky is widely known for its beautiful scenery in rural areas. Although the population of rural Kentucky has declined in recent years, an estimated 1.99 million Kentucky residents still live in rural areas as of 2020 (Kentucky League of Cities, n.d.). This large rural population disproportionately faces medical disparities originating from unique fundamental factors. In addition to generalized causes of inequities, healthcare disparities in rural areas stem from a variety of root causes specific to the rural setting. These include, but are not limited to, an inability to travel long distances to see a physician, a general lack of education and knowledge of how to utilize the healthcare system as a patient, economic barriers to medicine, and a lack of opportunities for medical care within rural areas (Weinhold and Gurtner, 2014).

However, many Kentuckians in urban locations also experience health disparities stemming from similar or overlapping issues. As of 2020, an estimated 2.52 million Kentuckians now live in urban locations, meaning that a little over half of Kentucky's current population now lives in urban locations (Kentucky League of Cities, n.d.). Therefore, many Kentuckians face disparities resulting from urban health insufficiencies. Low socioeconomic status is a major factor of medical disparities in urban populations. A low socioeconomic status can influence healthcare for all ages, but it is especially detrimental in childhood and adolescence. This early lack of medical access leads to lifelong medical consequences and a precedent that confines the child to future medical disparities (Fiscella and Williams, 2004; Braveman and Barclay, 2009). In 2022, it was found that 16.5% of Kentucky's residents live in poverty while 6.7% of Kentucky

residents do not have health insurance (U.S. Consensus Bureau, 2022). So, of Kentucky's 4,512,310 residents (U.S. Consensus Bureau, 2022), 744,531.15 Kentuckians are living in poverty while 302,324.77 Kentuckians lack health insurance. Thus, a large percentage of Kentucky residents, both rural and urban, face socioeconomic-related medical disparities that can greatly affect their entire lives. This poverty level creates a further barrier between citizens of Kentucky, both urban and rural, and adequate healthcare access.

These barriers to medical access and their associated lifelong consequences are especially important for children who face life-altering chronic health conditions that require specialized medical attention. More specifically, T1D is a growing pediatric chronic health condition that requires specialized, complex medical treatment for the patient to both survive and thrive. In Kentucky, the CDC states that the prevalence rate of T1D, or the number of cases per number of people, is about 14.7 children with T1D per every 10,000 children in Kentucky (Rogers *et al.*, 2018). In 2015, the CDC reported 950 cases of pediatric T1D in Kentucky (Rogers *et al.*, 2018). But, with 22.5% of Kentuckians being younger than 18 years old (U.S. Consensus Bureau, 2022), there are now about 1,015,269.75 children living in Kentucky. Using the reported prevalence rate, it follows that there are a predicted 1,492.45 children living with T1D in Kentucky today. This excludes adults living with T1D. Furthermore, with such a large rural population and low socioeconomic prevalence in Kentucky, it follows that many of these children face pediatric healthcare disparities and a lack of medical resources for their incurable, lifelong condition.

Therefore, to address this serious medical condition and the disparity affecting children in our state, I have developed Kentucky Diabetes Family Day (KDFD). The goal of KDFD is to connect children and families experiencing a new T1D diagnosis with life-saving healthcare resources and medical education. To accomplish this, KDFD aims to address each of the three general fundamental pillars that Tseng and Seidman (2007) cite as the basis of a social system while also characterizing T1D medical care using Meadow's (Meadows and Wright, 2008; Meadows, n.d.) more specific characterization of systems that breaks systems down into their precise building blocks. Since a common fundamental cause of healthcare disparities in both urban and rural areas is a lack of access to resources, KDFD aims to provide access to medical resources and education to the growing population of families and children newly diagnosed with T1D in Kentucky. The event connects families with representatives from pediatric endocrinology clinics, vendors of medical supplies, and people with T1D who can help guide them during their diagnosis. This addresses the pillars of systems focused on access to and availability of resources through providing direct access to medical supply companies, pediatric endocrinology clinics, and physician services. KDFD also prioritizes community building with a supportive community of people experiencing T1D in Kentucky through providing age group events, or time in which parents and kids can create their own community with others in their situation and age group, volunteers with T1D who participate in group discussions to facilitate conversation, and a Q&A panel of people with T1D. This addresses the pillar of systems focused on social interactions. Additionally, to address the socioeconomic aspect driving rural and urban health disparities, this event aims to connect families with financial resources through the medical companies hosted, includes catered breakfast and lunch, and is free to attend for all

participants. Thus, KDFD aims to improve access to medical resources to families experiencing new T1D diagnoses in Kentucky, foster communication between medical providers, and connect medical providers of urban locations to rural communities to improve communication and allocation of resources across Kentucky. These three aims align with the three pillars of a social system defined by Tseng and Seidman to lead to system-wide changes and repercussions. These three aims can be further dissected into their precise building blocks and interconnections using Meadow's more specific characterization of systems to identify precise key interconnections within the system to alter in order to create fundamental, large-scale change within a system.

This thesis aims to address Kentucky's health disparities, especially those affecting children with T1D, by characterizing the healthcare system in terms of Meadow's specific and detailed breakdown, using this characterization to both identify aspects of the system susceptible to change and to actively change this system fundamentally.

Background Research

The healthcare system in Kentucky, and more generally in the United States, harbors many medical disparities that affect certain groups disproportionately and in devastating ways. As defined by the Centers for Disease Control and Prevention (CDC), "Health disparities are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations," (line 1, 2020). From infants to the elderly, these health disparities cause people to grow sicker and even die from treatable and preventable illnesses and diseases. While these preventable disparities are currently being maintained in our society, we could remedy them and provide better and more accessible healthcare to everyone. By thinking about healthcare as a system, we can begin to identify its structure, how it functions, and its goals. Thus, we can identify changeable aspects within the system of healthcare to improve medicine for those affected by disparities.

Health Care as a System

A system is an organized structure aimed at achieving a specific goal. Tseng and Seidman (2007) characterize social systems based on the social interactions that comprise them, as well as their corresponding resources and how these resources are allocated within the system. More specifically, systems are characterized by three aspects: elements, or the individual basic aspects that together create the system, interconnections, or the interactions between the basic elements, and function, or the goal of the system (Meadows and Wright, 2008, p. 11; Figure 1).

Within a healthcare system, the ideas of social interactions, resources, and resource allocation from Tseng and Seidman's characterization of a system are directly related to disparities. However, we must think more critically to dive deeper into Meadow's characterization of systems while incorporating the general ideas given by Tseng and Seidman. Within a healthcare system, we can deduce that the basic elements include physicians and medical professionals, clinic and hospital coordinators, patients, physical medical facilities, medical supplies, the cultural and regional attitude surrounding healthcare in rural and urban

locations, among other things. Each of these elements are physical or abstract basic items that add together to create the whole of the functioning system. Medical supplies also reflect the general idea of resources postulated in Tseng and Seidman's model.

These elements are connected and related to each other by interconnections. Interconnections can include both physical interactions between physical elements and intangible interactions, such as communication networks (Meadows and Wright, 2008, p.14). Within the general healthcare system, the interconnections between elements include the distribution of resources, the utilization of resources, finances and the movement of money, communication pathways such as those between patient and provider and those between urban and rural clinics, and political policy. The communication pathways and distribution of resources interconnections reflect the general characterization given by Tseng and Seidman. These interconnections and elements work together to reflect the function, or purpose, of the system.

However, it is important to note that the function of a system must reflect the actions of that system, and not simply its ideals (Meadows and Wright, 2008, p. 14). A mismatch between actions and ideals may cause differences between an intended function and the actual function of a system, as is seen in health care. In general, the intended function of the healthcare system in Kentucky is to support the health of all Kentucky residents. When reviewing the mission statements of many prominent hospitals in Kentucky, they share the common theme of treating those in their community or state equally to promote the health of Kentuckians in the state or within their region of care (UK HealthCare, n.d.; UofL Health, 2021; Baptist Health, n.d.; Owensboro Health, n.d.; Med Center Health, n.d.). However, the general healthcare system of Kentucky, and more broadly of America, continues to perpetuate preventable disparities, leaving disadvantaged populations to be disproportionately negatively affected. These actions do not reflect the intended function shared in mission statements across the state. In reality, the true function of this system is to support the select elite and socioeconomically advantaged Kentuckians, or those who have the education, finances, access to transportation, and other necessities to be able to afford and utilize medical resources. Due to the perpetuation of disparities, the intended purpose of supporting all Kentuckians within the treatment radius becomes a subpurpose, or a secondary purpose layered under the overshadowing primary purpose (Meadows and Wright, 2008, p. 15). While the primary goal of most physicians and healthcare providers is to help others in their community in an equitable manner, the system as a whole does not.

This true purpose is further reflected in the stock, or the collection of resources resulting from the system functioning with time (Meadows and Wright, 2008, pp. 17-18), of this system. The stock is earned based on system functioning, and so represents what is most vital and sought after within the system. In an ideal world in which the intended function acted as the actual function, the stock would reflect the goal of supporting the health of all Kentuckians. As such, the stock may be the

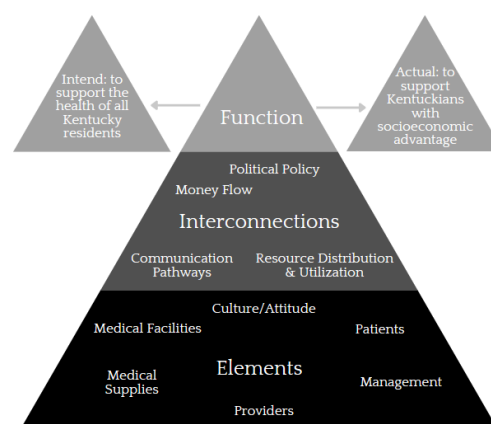


Figure 1. Illustration of the identified elements, interconnections, and function that characterize Kentucky's health care as a system.

level of health in Kentucky, with the system gaining statewide health as it provides for patients. However, this is not true for our actual healthcare system. In America, our for-profit healthcare system uses money as its form of stock. Therefore, rather than focusing on patient health, Kentucky's medical system approaches patient care as a financial interaction, in which the patient's poor health and need for expensive treatment is a source of increased stock and value within the system. The system would then lose stock if it treated every Kentuckian equitably, as a larger percentage of the population would be in good health and purchase less medicine. With the emphasis of American health care placed on money rather than patients, the system demonstrates that it does not support the intended purpose and the commitment to serve all, but rather to serve those advantaged enough to acquire care. This makes sense with the idea of a for-profit healthcare system, since, according to Meadows, "An important function of almost every system is to ensure its own perpetuation," (Meadows and Wright, 2008, p. 15).

So, in general, the idea of medical practice in both Kentucky and America fits nicely into the structure of a system. Next, we can begin to identify changeable aspects within this system to reduce specific disparities in Kentucky, both generally and with a specific example.

Disparity with Pediatric Type 1 Diabetes

While we often think of healthcare disparities as a general problem in society, we can focus on their effect on specific groups and patient populations to better understand how they interact within systems. Thinking about disparities in connection with specific groups and outcomes increases awareness of the impact that those disparities have on communities, while also more obviously highlighting aspects of the system that correspond with disparities. Here, the focus will be placed on the medical disparities experienced by people, especially children and young adults, living with T1D in Kentucky.

T1D is a life-long autoimmune disease caused by the body attacking its own pancreatic beta-cells, or the cells on the pancreas that create insulin for the body. This lack of insulin, or the compound the body relies on to derive energy from dietary sugar, causes hyperglycemia, or high blood glucose, and requires the person to use pharmaceutically created insulin, typically through an insulin pump or daily injections, to replace the body's insulin and be able to live (JDRF, n.d.). Thus, people with T1D must constantly manage their blood glucose levels and learn to adjust their insulin to properly respond to food intake and factors that can affect blood glucose such as previous or planned exercise and activity, stress, alcohol, medications, and type of food. People with T1D must make a daily average of 180 decisions about their T1D alone (Tack *et al.*, 2018).

While a lack of insulin can cause hyperglycemia, too much insulin can cause hypoglycemia, or low blood glucose. So, people with T1D experience both high and low blood glucose levels during their self-management. If T1D is left out of control, people with T1D can experience a multitude of long-term serious health complications stemming from prolonged hyperglycemia. Some of these health conditions include damage of blood vessels, diabetic retinopathy, diabetic nephropathy or kidney disease, diabetic neuropathy or nerve damage leading to lower limb amputations, and heart disease (Smith-Marsh, 2017). Each of these are serious health conditions that could cause permanent damage or death to the individual over time. However, not all

dangerous complications of T1D are due to long-term mistreatment. Emergency situations can arise even when T1D is well managed. This is because some aspects of daily life, such as illness and exercise, can greatly impact blood glucose levels in a way that is sometimes difficult to treat even if the effects are predictable. Diabetic ketoacidosis (DKA), a dangerous accumulation of acidic ketones in the body that can lead to serious complications and death, can occur rapidly and cause death from acidosis, dehydration, and an imbalance of potassium (Centers for Disease Control and Prevention, 2022; Zero to Finals, 2019). Similar to the long-term complications, DKA occurs due to a lack of insulin or prolonged hyperglycemia, but over a shorter time period. Without insulin to break down glucose into energy, the body uses fat as a source of energy. However, this process produces the deadly ketones, creating an emergency situation (Centers for Disease Control and Prevention, 2022). Immediate emergency situations also arise from severe hypoglycemia. While hypoglycemia brings sickly symptoms, such as weakness, fatigue, hunger, sweating, dizziness, and confusion, severe hypoglycemia can result in faints and seizures. These seizures can result in death in extreme cases. Most instances of hyper- and hypoglycemia do not result in these negative health consequences and are relatively simple to treat after having proper training and with the proper medicine, but emergency situations can and do occur.

With this brief description of T1D, it becomes evident that T1D is a complex disease that is affected by many aspects of daily life, and that also affects aspects of daily life itself. The complex factors affecting insulin management and the potential illness and emergency that follows a mistake or poor management illustrates the disease complexity and intensity that leads to those extra 180 decisions per day (Tack *et al.*, 2018). To emphasize this idea, I have included my own personal “DiaDigits,” calculated by JDRF (n.d., *The DiaDigits*). My “DiaDigits” illustrate the amount of blood glucose tests, insulin injections, hours experiencing low blood glucose, and hours of sleep lost in the amount of time that I have had T1D (JDRF, n.d., *The DiaDigits*; Figure 2). Each blood glucose test, insulin injection, and low blood glucose required at least one decision in my treatment plan. How much insulin should I take based on the amount of carbohydrates I calculated, my current blood glucose level, and my planned activity for the next two hours? How much sugar should I eat to correct this episode of hypoglycemia without accidentally sending myself into a hyperglycemic episode? How will I perform on my math test tomorrow after being awake treating my blood glucose all night long? These are questions and decisions that children with T1D must make an average of 180 times a day.

T1D is a disease that, while incurable, is manageable with insulin therapy, blood glucose monitoring, and help from an endocrinologist. However, many patients experience the dangerous complications resulting from not treating their T1D. While it is true that there are some people who do not attempt to manage their T1D even with resources available, this is not true for many

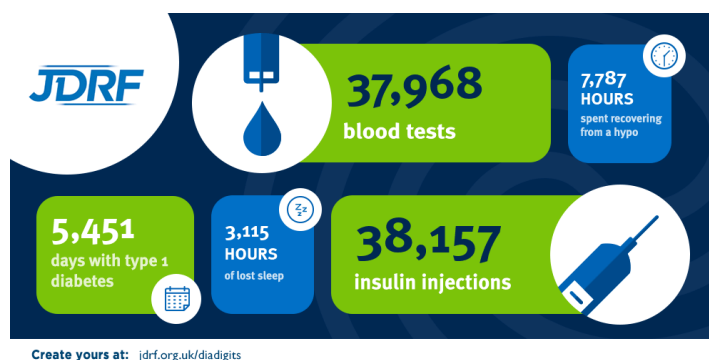


Figure 2. My personal “DiaDigits” calculated by JDRF’s “DiaDigit Calculator.” This quantifies various T1D decisions that I have made in the past 15 years that I have had T1D (JDRF, n.d., *The DiaDigits*).

Kentuckians and Americans. Many Kentuckians and Americans experience the causal factors of health disparities in their daily lives, preventing them from accessing the necessary medical care and from managing their own or their child's T1D, leading to unnecessary, preventable injury, comorbid disease, and death. With T1D most often arising in childhood, factors like DKA resulting from undiagnosed T1D in an area lacking access to specialized pediatric health care or DKA resulting from an inability to access insulin due to barriers from their parents' low socioeconomic status often affect children who are unable to advocate for and provide for themselves. Children are not exempt from the immediate and long-term health complications associated with T1D, nor from the effects of disparities that are perceived as perpetuating in the "adult world." Ruiz *et al.* (2022) noted that the standard mortality rate is about four times increased for people with T1D than for those without in America (Figure 3). This increased mortality directly stems from disparities preventing T1D treatment in America. Of note, the same study indicated that this difference in standard mortality rate between people with and without T1D was highest in America and lower in many other countries (Ruiz *et al.*, 2022; Figure 3). This is important to note, because this illustrates that the difference in mortality rate stems from disparity and differences in healthcare systems rather than in disease progression itself. We can create change to better serve people with T1D, provide care that is more equitable for all, and reduce the harm children experience from this disparity.

Interconnections and Disparity in Kentucky

In striving to change a system, it is important to connect the aspects of a system with the errors to which they correspond. In medical disparities in Kentucky, both general disparities experienced by rural and underserved populations and the specific disparity revolving around T1D, we can connect the specific aspects of the interconnections between elements in the medical system with aspects perpetuating disparity to identify areas of change.

When altering systems to change their outcomes, it is most effective to alter their interconnections (Meadows and Wright, 2008, p.16). Altering the specific elements is often very ineffective (Meadows and Wright, 2008, p. 16). This minimal effect can be seen by physicians and medical professionals who practice with the intended purpose of the system in mind. The effect these professionals have on the system is minimal, because the disconnect between the function of this single element and the function of the entire system is not sufficient to create systematic change. Altering the function of the system can create radical changes to the entire system and so is also an effective way to alter outcomes (Meadows and Wright, 2008, p.16). However, in the case of medicine, many of the identified interconnections pair with driving factors of disparity, allowing for more achievable methods of intervention for dramatic and quick change.

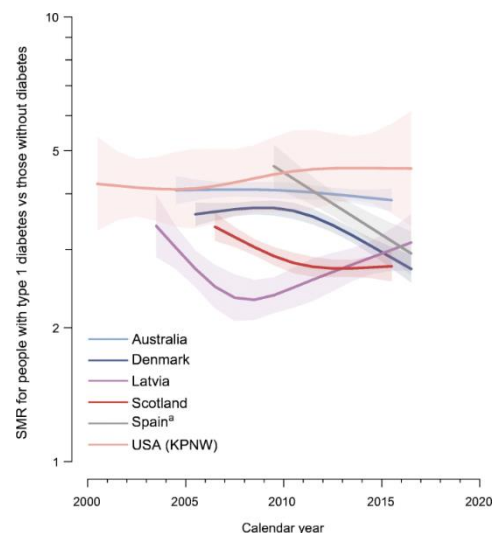


Figure 3. Graph illustrating differences in standard mortality rate (SMR) for people with and without T1D over time in different countries (Ruiz *et al.*, 2022).

Distribution and Utilization of Resources

One key interconnection affecting underserved populations, especially those in rural areas, is the distribution and utilization of resources. This interconnection doubles as a defining aspect of a system identified by Tseng and Seidman (2007), and so is an important aspect of this system. In this context, distribution of resources means the availability of adequate health care, specialized health care, and medical providers, while the utilization of resources refers to the ability to access these resources. The maldistribution of providers and medical resources not only reflect aspects of disparities related to the distribution of resources interconnection, but also compound with barriers to accessing resources to perpetuate quality discrepancies and disparities relating to the utilization of resources (Weinhold and Gurtner, 2014).

Maldistribution of providers refers to the availability of doctors within a given area. Rural areas often lack a sufficient number of physicians to care for the population. Moreover, specialized physicians are not moving to rural areas (Weinhold and Gurtner, 2014). This leads to a lack of medical opportunities for the populations of these rural areas, contributing to the lessened quality of health care experienced by rural populations in comparison with urban populations.

The lack of physicians in rural areas can be seen in Kentucky. In 2019-2020, Kentucky's 4,467,673 residents were served by a total of 10,528 physicians (AAMC, n.d.). The UK Center of Excellence in Rural Health (2022) showed that in 2022, 25.2% of these physicians were located in rural areas, 16.6% being in Appalachia, while 74.8% of these physicians were located in urban areas. The UK Center of Excellence in Rural Health then broke this distribution down into the number of physicians per county and showed the lack of physicians within rural Kentucky counties. Many rural Kentucky counties had fewer than 10 physicians serving the entire county, while seven counties had zero physicians serving them (UK Center of Excellence in Rural Health, 2022; Figure 4).

This lack of providers and specialists combined with a lack of the medical resources themselves exacerbates this difference in the quality of care in both the immediate and long-term disease treatment. A lack of providers makes it difficult for people in a rural area to build connections with their primary physician to receive long-term care, as well as with physicians of other specialties to receive coordinated care (Weinhold and Gurtner, 2014). This

Distribution of Physicians By County

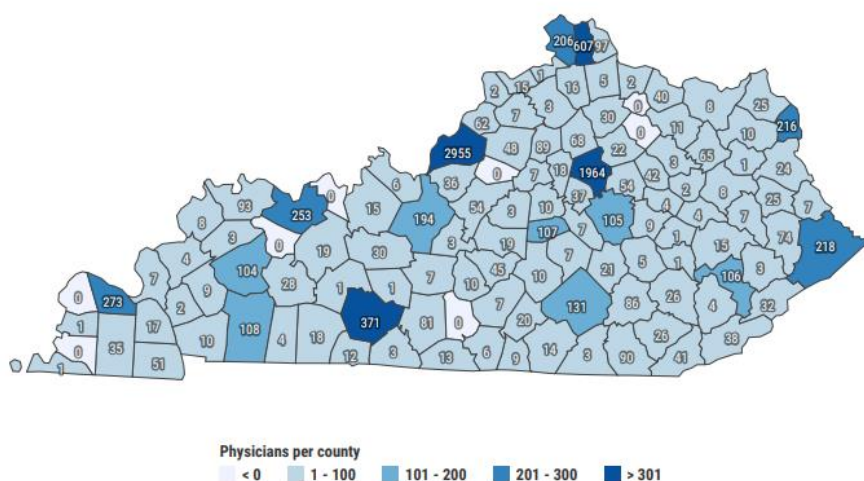


Figure 4. Map created by the UK Center of Excellence in Rural Health in 2022 illustrating the total number of physicians per county. The county with 2,955 physicians includes Louisville, while the county with 1,964 physicians includes Lexington (UK Center of Excellence in Rural Health, 2022).

type of long-term coordinated care is what kids with T1D must experience in order to effectively treat and manage their T1D.

Further, the idea of lacking providers does not only affect people in rural areas. As much of Kentucky's population is becoming more urban, the distribution of people does not reflect the distribution of physicians. An estimated 31% of Kentucky's urban population lives in the Louisville Metro area and 13% live in Lexington, while the remaining 56% of urban Kentuckians live elsewhere (Kentucky League of Cities, n.d.). This includes areas such as Owensboro, Bowling Green, and Paducah. However, the UK Center of Excellence in Rural Health (2022) has shown that these areas, while hosting more physicians than most rural counties, have significantly fewer physicians when compared with Lexington and Louisville (Figure 4). Therefore, while urban areas of Kentucky are served by more physicians than rural areas, the distribution of physicians is highly concentrated on the Lexington and Louisville areas, while other urban areas are not necessarily served by a proportional number of physicians to serve both the city and residents of the surrounding counties who are seeking nearby health care. Plus, the distribution shown in Figure 4 does not include a breakdown of those physicians by specialty. This further illustrates the potential lack of both adequate and appropriate medical services in both urban and rural areas of Kentucky. Furthermore, in urban areas, community health centers, or health centers dedicated to providing medicine to people of low socioeconomic status, are lacking in physicians available to provide this treatment (Fiscella and Williams, 2004). The services available in underserved urban and rural areas are depleted and insufficient for the entire population's need. Therefore, maldistribution and the lack of providers is a common problem across rural and underserved urban populations alike.

In addition to a lack of resources, people in rural areas experience barriers to accessing the available resources. Barriers induced by geographic location making the commute to the doctor difficult or lacking a mode of transportation to reach the doctor's office prevent people from accessing adequate health care (Weinhold and Gurtner, 2014). Due to the lack of medical specialists in rural areas, this is another common barrier to T1D care.

Kids with T1D must see a pediatric endocrinologist every three to six months for routine check-ups to maintain appropriate care. These clinics are often found at large hospitals in large cities that are located a long distance from their hometown. In Kentucky, there are only two pediatric endocrinology clinics in the entire state: UK HealthCare's Barnstable Brown Diabetes Center and Norton Healthcare's Wendy Novak Diabetes Institute. So, families in other parts of the state needing this care must drive to one of these locations. For most of the state, that drive is multiple hours. Plus, there are only 68 endocrinologists total in the state, servicing 65,701 patients each (UK Center of Excellence in Rural Health, 2022). This ratio illustrates a gross lack of endocrinologists available within the state to sufficiently serve the entire state in a caring manner. The lack of physicians available both closer to their hometowns and within the state makes it more difficult for families to find and access available healthcare resources, leading to the lack in treatment options that causes kids to become very ill and die of this disease.

Finances and Movement of Money

Another key interconnection of this system that directly relates to healthcare disparities in both urban and rural populations is the finances of health care and the movement of money within the healthcare system. When considering money itself as the stock of the healthcare system and the impact of low socioeconomic status on patients, we can conceptualize the interconnection of money movement by determining sources and sinks within the system. Meadows describes sources as places where stock originates, while sinks are places where stock is removed from the system (Meadows and Wright, 2008). Regarding the movement of money within this system, the source of the money originates from the patients, or the agency that pays for the treatment on behalf of the patient such as private health insurance companies or federal agencies. Thus, the system as a whole earns money that is saved as stock. As the money flows, this stock of money is removed from the system at the sinks. The sinks are the locations or purposes to which the money from the stock is spent (Meadows and Wright, 2008), such as hospital care and prescription medicine, thus reducing the stock. (Figure 5). With the source originating from the patients or the organizations paying for treatment on behalf of them, this introduces an obvious interconnection for disparity to prey upon.

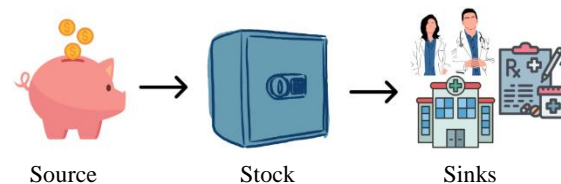


Figure 5. A stock-and-flow diagram of the flow of money in the conceptualized healthcare system. The source is money from patients. The stock is the money earned by the system. The sink is the expenditures for hospital care, physician services, and prescription drugs.

Our healthcare system places a financial burden on patients, as patients must typically pay for medical services. In America, the 2021 national medical expenditure was \$4,255.1 billion. Of this total cost, 10.2% was paid out-of-pocket, or from the patient's own money, rather than by insurance or other means. Another 28.5% was paid by private health insurance companies (American Medical Association, 2023). Paying out-of-pocket places a great and often unexpected financial burden on families, and many Americans are unable to afford a plan with a private health insurance agency. Plus, while there are options for gaining help in paying this financial obligation from the federal government and other medical resources, these options are not always accessible or available to every person, do not completely alleviate the financial burden of medical expenses, and do not help decrease the economic barrier to medicine that is felt by everyone. More specifically, with 16.5% of Kentucky residents living in poverty, 6.7% lacking health insurance, and 22.3% using Medicaid, the financial burden is clearly felt by Kentucky residents (U.S. Census Bureau, n.d.; Vankar, 2022). So, the movement of money introduces an area for health disparities to thrive, leading to a disproportionate, negative healthcare experience for people of low socioeconomic status as this status often prevents families from being able to access and afford medical care.

Low socioeconomic status affects rural and urban families alike. For both rural and urban families, the inability to afford expensive medical treatment prevents patients of all ages from receiving the treatment they need. Whether common medical treatment like hospital visits or more specific medical treatment like utilizing the services of a specialized physician, not accessing medicine directly leads to worsened health and, possibly, death. Aside from affording the treatment itself, a low socioeconomic status could prevent patients, especially those in rural areas, from accessing medical care. If patients must travel long distances to see physicians, then they must pay for transportation. From the gas for a personal vehicle, to ambulance rides, to public transportation, this is expensive and can be unaffordable, especially on top of the actual cost of the medical service. Moreover, many rural areas do not have access to public transportation, meaning that patients must have their own, reliable personal vehicle to reach treatment. Even for patients who have health insurance, Medicaid, or some other assisted payment plan, the price and availability of transportation may prevent them from ever reaching the doctor's office. So, patients who are unable to access treatment due to barriers from their socioeconomic status experience poor health (Figure 6).



Figure 6. A schematic representation of the cycle of low socioeconomic status affecting health.

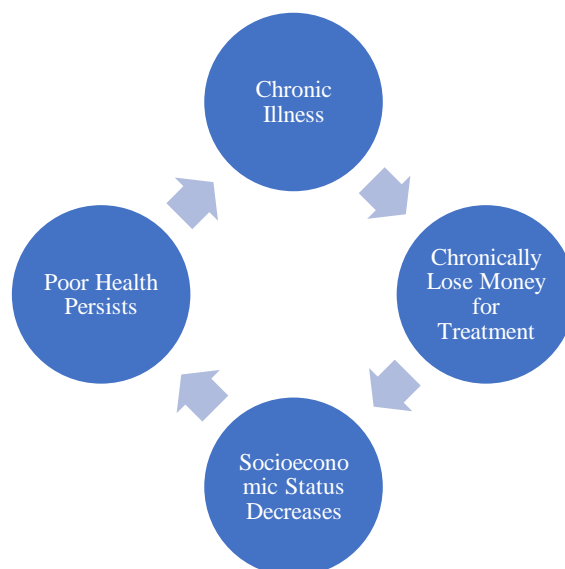


Figure 7. A schematic representation of the cycle of reverse causality.

However, the reverse is also true. With the concept of reverse causality, people with worsened health, which results in the financial burden of medical services, can cause low socioeconomic status (Fiscella and Williams, 2004). So, families may develop low socioeconomic status over time due to a new or present medical demand, such as a new chronic illness, then be unable to afford healthcare in the future, thus introducing disparity (Figure 7). Whether originating from familial socioeconomic status or prolonged chronic health, people experiencing this disparity experience barriers to necessary treatment.

Without treatment, poor health is perpetuated and worsened, leading to potentially avoidable consequences. This effect persists throughout one's entire life, as demonstrated by life-

course studies, which illustrate the lifelong and generational effect of low socioeconomic status on health outcomes (Braveman and Barclay, 2009). The effect on health of having a low socioeconomic status could begin at the fetal stage, as the low socioeconomic status of the mother detrimentally affects the health of the mother herself, thus detrimentally affecting the health of the fetus (Fiscella and Williams, 2004). Following this idea of fetal stage importance, the Baker Hypothesis identifies the fetal stage as a “critical period” in which varying fetal experiences, such as the negative health-related experiences resulting from a low socioeconomic status, lead to developmental harm of key body parts and biochemical processes of the fetus that, in turn, lead to adult chronic illness (Braveman and Barclay, 2009). In addition to affecting adulthood, this effect on the developing fetus also follows the babies to childhood. Children of low socioeconomic status experience a much greater risk factor for some chronic illnesses, health issues arising from abnormal development, conduct and behavioral discrepancies, infectious disease, and death. Finally, as indicated by the Baker Hypothesis, this effect then follows the children to adulthood, where the mortality risk factor greatly increases for those of low socioeconomic status (Fiscella and Williams, 2004). Life-course studies support this idea through defining the health effects that arise from varying the order and frequency at which patients experience medical setbacks, such as those due to a low socioeconomic factor. An example of this is the idea of cumulative risk, which suggests that the additive combination of detrimental factors, such as low socioeconomic status, across one’s life leads to worsened health over time (Braveman and Barclay, 2009). With the increased likelihood of poor health from childhood to adulthood arising from this disparity, the cycle is able to continue again. As the affected children become adults with poor health, then become parents with poor health, this cycle can be repeated and the disparity can be passed on to the next generation (Figure 8).

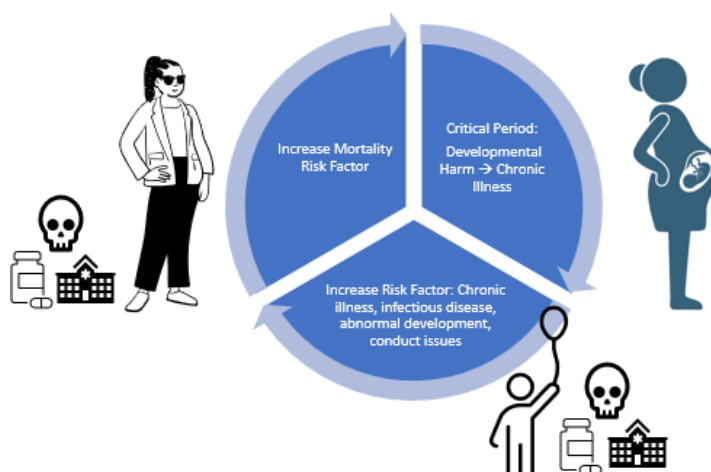


Figure 8. A schematic representation of Baker’s Hypothesis and the life course perspective perpetuating socioeconomic disparity and poor health across both lifetimes and generations.

The effect of a low socioeconomic status on medical access and life-long health outcomes can be seen more specifically with pediatric T1D. In general, families of kids with T1D have more medical expenses than unaffected families due to the financial obligations of the

medical supplies and appointments necessary for treating T1D and other commonly associated comorbid afflictions. Since uncontrolled T1D can cause a variety of serious, irreversible health issues and even death, this socioeconomic disparity is even more critical. When looking at the total cost of American medicine in 2021 broken into its constituents, three large expenses, or sinks, in this total expenditure were hospital care, comprising 31.1% of the total expense, physician services, comprising 14.9% of the total expense, and prescription drugs, comprising 8.9% of the total expense (American Medical Association, 2023). These specific categories greatly affect people with T1D.

T1D can cause emergency situations through diabetic ketoacidosis and extreme hypoglycemia. So, hospital stays can be common for people with T1D, whether due to an unpredicted emergency situation resulting from undiagnosed T1D, or from emergency situations after diagnosis. Plus, the aforementioned comorbid health complications that result from long-term hyperglycemia can lead to serious complications as well, such as heart disease leading to heart attack and kidney disease leading to acute kidney failure. This adds to the prevalence of people with T1D staying in the hospital. People with T1D are also bound to physician services for life, even if their T1D is well controlled and they no longer need treatment advice from a physician. From training upon diagnosis, to assistance while learning to manage T1D and make adjustments to insulin therapy doses, to needing a physician to authorize prescriptions of insulin and T1D technology, people with this incurable disease must have frequent check-ups with physicians for their entire lives. Add in the comorbid diseases from mismanagement and these patients must seek the services of multiple treatments. People with T1D also rely on prescribed insulin to survive, and often use technology such as insulin pumps and continuous glucose monitors to aid in management. Almost everything a person with T1D uses to treat their condition, from emergency glucagon to use during severe hypoglycemia to the cannulas used with an insulin pump to infuse insulin, are prescription based. Plus, a correlation has been found between T1D and other autoimmune diseases, namely thyroid disease, among others such as gastritis and celiac disease (Witek *et al.*, 2012). While many of these can require other physician services than those provided by an endocrinologist, thus adding to the physician services expenditure, many of them also require separate prescription drugs, as do the comorbid diseases associated with uncontrolled T1D. So, patients with T1D heavily contribute to the medical financial burden of hospital visits, physician services, and prescription drugs. Combined with the percentage of patients who pay out-of-pocket, lack insurance, or rely on Medicaid, this places a heavy medical financial burden on patients with T1D and low socioeconomic status. Thus, people with T1D and low socioeconomic status may have immense barriers to medical care, leading to worsened health. Furthermore, with the concept of reverse causality, people with T1D may develop a low socioeconomic status due to their personal expenditure on their medical care. So, these patients are susceptible to disparity both from experiencing low socioeconomic status before diagnosis, and from developing low socioeconomic status after diagnosis. This leads many patients to lack the care they need to be healthy and survive.

Moreover, this financial burden is felt more for families of kids with T1D than for adults with T1D. While the average yearly out-of-pocket cost of T1D care is \$2,500, a cost which varies greatly with insurance types and increases dramatically without insurance, Michigan

Medicine reports that this cost is about \$823 per month for kids with T1D and \$445 per month for adults with T1D (Mostafavi, 2020). Thus, there is an even larger socioeconomic barrier in place for children than for adults, making it more difficult for families to afford and access health care and all the more likely for kids to become ill and die.

Because T1D is incurable, this expense affects families and people during all life stages after diagnosis. To characterize this lifetime cost, we can extrapolate from the average monthly costs for adults and children with T1D to calculate the average annual cost of having T1D, which is about \$9,876 for children and \$5,340 for adults. Further, we can calculate the average lifetime cost of having T1D using the peak diagnosis ages reported by Mayo Clinic (2022), or “between 4 and 7 years old” and “between 10 and 14 years old,” to determine the average ages of diagnosis to be about 5.5 years old and 12 years old and using average life expectancies (Mayo Clinic Staff, 2022). The National Vital Statistics System from the National Center for Health Statistics and the CDC stated that the average US life expectancy in 2021 to be about 76.1 years old (Arias *et al.*, 2022), while a 2022 prediction of the average life expectancy for people with T1D was about 65-72 years old (Burke, 2022). Both life expectancies were considered because with treatment, people with T1D can have lifespans typical of the average person without T1D. However, without care, either due to inability to treat disease or noncompliance with treatment, diabetes can lead to a shortened lifespan. Thus, the average lifetime cost for a child with T1D ranges from \$328,926 to \$433,704 depending on lifespan and age at diagnosis (Table 1).

Table 1. Calculating the average lifetime cost of health care for a person with T1D based on average life expectancies with (Burke, 2022) and without (Arias, 2022) T1D, average ages at diagnosis (Mayo Clinic Staff, 2022), and average monthly expenditures for adults and children with T1D (Mostafavi, 2020). Lifetime cost was calculated using the following formula:

$$((18 - \text{age of diagnosis}) * (\text{average cost of T1D for children})) + ((\text{average life expectancy} - 18) * (\text{average cost of T1D for adults})) = \text{Lifetime cost}$$

Life Expectancy	Age at Diagnosis	Lifetime Cost
76.1 years	5.5 years	\$433,704
76.1 years	12 years	\$369,510
68.5 years	5.5 years	\$393,120
68.5 years	12 years	\$328,926

This is a large sum of money that can rival and exceed mortgage payments. Factoring in the number of Kentuckians without health insurance and living in poverty or those families relying on out-of-pocket payments, this can create an immense barrier to healthcare that leads to lifelong and intergenerational socioeconomic disadvantage and poor health. And, with the concept of reverse causality, people of a higher socioeconomic status can lose this status due to the expenses that come with T1D and be unable to afford health care in the future, bringing the same extreme negative medical consequences experienced by patients with T1D. Although kids are not yet a part of the real world, they are starkly affected by this reality. And, as shown by the life-course

study model, these kids will experience poor health throughout their entire lives and carry on a generational legacy of poor health. Poor health will then increase medical bills, leading to the perpetuation of this disparity for generations.

The effect of having a low socioeconomic status not only affects children's access to medicine for T1D treatment, but also their general health outcome in life via the life-course perspective. Plus, children from families with low socioeconomic status have an increased risk for many detrimental health factors, including infectious disease (Fiscella and Williams, 2004). This is doubly significant for children with T1D, as infectious disease can cause pediatric T1D due to initiating an autoimmune response, but is also detrimental after diagnosis. After diagnosis, infectious diseases can lead a person into diabetic ketoacidosis. Also, patients become more susceptible to infectious diseases as T1D management worsens, creating a dangerous cycle (Piccolo *et al.*, 2022). Overall, this dangerous cycle perpetuates general illness, worsened T1D-related health outcomes, and negatively affected socioeconomic status chronically over time (Figure 9).

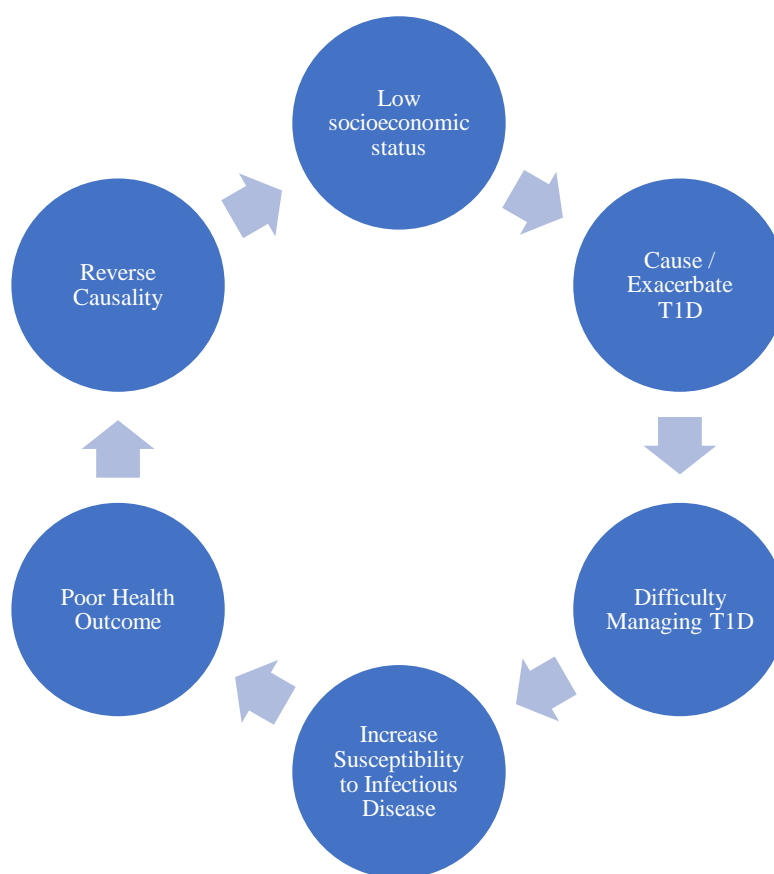


Figure 9. A schematic representation of the cycle perpetuating poor health and weakened socioeconomic status specifically for children with T1D.

All in all, poor health and low socioeconomic status not only create a cycle between each other, but also cause health issues throughout a person's entire life. Kids with T1D from families of low socioeconomic status will experience poor health that endures throughout their lives, and potentially create a generational legacy of poor health.

Communication Pathways

The communication pathways that comprise our healthcare systems are another important interconnection involved in health disparities. Not only do these pathways comprise an interconnection of the system, but they also reflect the social interactions that Tseng and Seidman require as a defining aspect of a system. Communication pathways in health care break down both between patients and providers, and between urban and rural locations.

There are a plethora of factors inhibiting communication between physicians and patients. In rural areas, much of the population is not educated about the use of medical opportunities or the meaning of medical situations (Weinhold and Gurtner, 2014). This creates a barrier between patients and providers, preventing patients from both seeking and understanding providers. This, then, creates fear and apprehension around the idea of medicine in rural areas. Underserved urban patients lacking this education could also experience this barrier. General attitudes can also affect communication. Rural patients often avoid care due to personal biases about the available care, internalized opinions about the nature of their own health, or expected future implications upon treatment (Weinhold and Gurtner, 2014). This further drives rural patients away from physicians, breaking down communication. Similarly, varying cultures affect the relationship and communication between physicians and patients (Weinhold and Gurtner, 2014). This is true for both urban and rural populations. As the breakdown in communication persists due to a lack of education, biases, cultures, and potential fears, an atmosphere of distrust builds that further weakens communication, preventing information flow from patient to physician and vice versa. Without physician trust or system-understanding, patients will choose not to or be unable to utilize the available healthcare resources and will experience poor health outcomes.

Communication pathways between physicians have also historically weakened between rural and urban locations through referral systems. Referral systems are communication pathways between generalist providers, such as family doctors or general practitioners, and specialist providers, such as cardiologists or neurologists. Typically, as a general provider discovers a patient's new health condition that needs more specific treatment than what they are trained to provide, the provider will refer the patient to a specialist provider. Generalist and specialist providers will continue to communicate about a patient to share changes in medical history, necessary information, and treatment plans. Thus, in this role, the generalist provider coordinates outside, more specific care for their patients with complex conditions. As such, the efficient communication of patient information and needs as well as physician information and needs is critical in ensuring patients receive the care they require in a timely manner. Historically, however, these communication pathways have broken down and left patients without proper care.

In 2000, primary care physicians and specialists both were unhappy with the referral system. The main complaints between the two groups, who utilized an array of referral methods from digital to paper forms, consisted of the miscommunications about what constituted appropriate and adequate information to send, and the amount of time it took to actually create the referral (Ghandi *et al.*, 2000). From 2006 to 2007, electronically transmitted referrals still

resulted in miscommunication. From discontinuation of referrals by specialists, to untimely or nonexistent follow-ups by primary care physicians, to miscommunication about the requirements for referral, the roots of miscommunication were not removed with increasing technology (Singh *et al.*, 2010). In 2011, review of the referral system between primary care physicians and specialists indicated that primary care physicians still over-referred patients inappropriately and under-referred patients when they should have been referred to specialists, with ratios of both cases being dependent on the medical condition. Furthermore, the study identified reports showing that no communication occurred between the primary care provider to the specialist more than 50% of the time, while no communication occurred in the opposite scenario in slightly under half of the referrals (Mehrotra *et al.*, 2011). So, historically in America, there has been a breakdown of communication between generalist and specialist physicians. Although this may be improving with the improving technology and tools for disseminating information between physician offices, I am currently unable to find updated studies on referral system efficiency at the time of this thesis. However, the underlying causes of miscommunication, such as the deficiencies in appropriate information and physician responses, appear to remain unchanged over time despite modified referral protocols. Inconsistencies in referral systems produce more barriers to medical care in addition to aforementioned physical barriers. Thus, the lack of communication between primary care providers and specialists has greatly affected the care received by patients in both urban and rural areas who need specialized, complex care. This not only provides barriers to care, but introduces complexity after referral. If the physicians are not communicating, then many aspects of health may go unnoticed. For example, comorbid symptoms may influence each other without discovery, medications may compete dangerously or counterintuitively, and assumptions may be made about which doctor is treating which condition. This last example could lead to neglected care or dangerous overtreatment in extreme cases.

Considering the prevalence of primary care physicians and the lack of specialists in rural areas, this can be extrapolated to reflect the communication between urban and rural physicians. Along with transportation and access barriers between these locations, communication with outside medical centers adds another barrier preventing rural populations from accessing adequate care and making these populations more susceptible to inadequate resources and inappropriate utilization of resources.

The lack of communication between patient and provider causes negative consequences on the health of people with T1D. If lacking education about utilizing the healthcare system, such as how to utilize a primary care physician to receive medical test to then receive a referral to a pediatric endocrinologist for T1D care, then many patients will not receive adequate care. Whether by settling for inadequate care or never reaching any care, patients with T1D will experience negative health effects due to an overall lack of care and support. Without proper communication between primary care physicians and patients with T1D, patients may struggle to find a physician with whom they feel comfortable, to integrate their T1D management into their daily health routine and into primary care check-ups, and, potentially, to identify how T1D and other aspects of health may be influencing each other. Patients may receive conflicting advice or competing medications from their specialists, resulting in confusing and damaging situations.

This may occur between many physicians for patients with T1D due to the occurrence of comorbid symptoms, leading to increasing complexity, confusion, and neglect for these patients.

Examples of this neglect can be seen in both America and, more specifically, Kentucky. The previous study from 2011 identified diabetes (unspecified type, nationwide) in the specific conditions of patients who were under-referred, stating that patients with diabetes were very often not referred to eye screening services and that pregnant women with diabetes were often not referred for necessary screening (Mehrotra *et al.*, 2011). Since both of these screening needs are necessary for people with T1D, this can be applied to people with T1D specifically. If these screenings are missed, dangerous complications with pregnancy and susceptibility to diabetic retinopathy and blindness could be missed. These two examples illustrate how extreme miscommunication can be for an individual patient's life. Additionally, a study more specific to Kentucky conducted by the Department of Pediatrics at the University of Kentucky College of Medicine found that while primary care physicians in counties of rural Appalachian Kentucky complied with published guidelines by the American Diabetes Association (ADA) detailing frequency of routine follow-up appointments for kids with T1D, they historically did not comply with guidelines detailing T1D treatment. Specifically, they violated standards of the frequency of blood glucose testing, evaluation for associated comorbid conditions, and frequency of insulin treatment (Schoepflin and Thrailkill, 1999). This could be a result of miscommunication between governing bodies and rural healthcare providers, or due to a lack of policy maintaining these guidelines. Either way, this history of mistreatment has caused many patients to lack proper medical care and experience negative health consequences. This perpetuation of miscommunication has directly contributed to the lack of appropriate medical resources available for people with T1D in rural Kentucky.

Methods

Reasoning – Methods to Create Change

To combat these disparities arising from interconnections, one must create fundamental changes to the system. In these methods, I focus on creating change at the interconnection level through identified leverage points. Meadows identifies leverage points as aspects of a system that, if changed, would elicit change across the whole system (Meadows, n.d.). In my effort to create change, I planned a state-wide medical event called Kentucky Diabetes Family Day (KDFD) that aimed to change a set of identified leverage points in the Kentucky healthcare system. KDFD is an interactive, conference-like event that includes participation from the state's two pediatric endocrinology clinics, representatives from major T1D technology and support companies, guest speakers who are medical professionals working with T1D, free catered breakfast and lunch, a giveaway of items necessary for people newly diagnosed with T1D, and time during which kids and parents are separated to build community amongst themselves. This event, including food and parking, was completely free for all attendees, and open to any person wanting to learn more about T1D management. The leverage points and interconnections I

addressed included socioeconomic parameters of individual families, the structure characterizing the distribution of resources, and the structure of communication pathways.

Meadows describes parameters as the basic motivators of stock fluctuation and as a relatively weak leverage point, except in the instances that the defined parameter affects leverage points that are considered to be a stronger influence on the system (Meadows, n.d.). Since patients are the source of money, and therefore the source of the stock accumulation, I identified patient finances as a leverage point. Theoretically, if enough patients cannot afford medical care, then the system could be threatened. However, in our medical system, this is highly unlikely due to the size and stability of the stock of money. So, the financial situation of patients, such as disparity caused by low socioeconomic status, would not be considered a high impact area of change in this systems-based model, and thus societal efforts will be placed more on reacting to this situation to help individual families than in preventing the disparity in the first place through fundamental change. Since I am unable to change the fundamental economic business model of the healthcare system on my own, I used this event to focus on creating change for individual families. I could not eliminate socioeconomic barriers to medicine for disadvantaged populations, but I could provide resources and connections to providers and medical supplies for free to all families. These resources would be difficult and costly to access individually without this event, and many would require the help of costly outside resources such as the need for a doctor's referral to meet new physicians in a new clinic. Plus, these companies (Dexcom, JDRF, Medtronic, Tandem, Insulet, Gvoke/Xeris Pharmaceuticals, ProventionBio, Gluconfidence, Camp Hendon, Barnstable Brown Diabetes Center, and Wendy Novak Diabetes Center), come equipped with knowledge of financial aid for their products, bringing solutions to this barrier to provide options and opportunities for individual families rather than for the system as whole. The event was also free for all attendees, including breakfast and lunch, to reduce further economic barriers. While this may not change the whole system, it greatly changes health outcomes for families as it relates to a more influential leverage point. Positive feedback loops are an influential leverage point that consist of outcomes growing in intensity over time (Meadows, n.d.). Families of low socioeconomic status feel this as the constant medical bills for people with T1D continue to drive them into a lower economic bracket over time. The resources at this event create an intervention into this snowball effect.

Addressing the leverage points found within the structure characterizing the distribution of resources affects the system more holistically than the previously described leverage point. It is difficult and costly to directly rebuild the structure of the distribution of resources, but great systematic change can be accomplished by identifying and addressing areas lacking adequate attention within the structure (Meadows, n.d.). For example, I cannot build a hospital and hire specialists in a rural area to overcome barriers to healthcare stemming from maldistribution of physicians and resources. However, I can connect families with providers and resources so that they can gain access to other resources that are already available, thus improving utilization of resources and associated health outcomes. So, to combat the identified disparity of maldistribution of resources and physicians, KDFD aimed to reduce the flaws in this structure found in rural and underserved areas. Rather than rebuilding the structure, the goal was to provide indirect structural support through connecting communities with the resources to which

they did not have access. Toward this end, KDFD hosted multiple physicians and representatives from the two pediatric endocrinologist clinics in the state and representatives from T1D medical supply companies, and provided designated time during the event for families to interact with these vendors to receive free information. This provided a cost-effective solution that both immediately provided families with resources, and also planted the seed to slowly improve upon resource availability and education of utilizing the already available resources within these underserved areas.

Perhaps the most effective leverage point for changing the whole system addressed by this event was that of the structure of communication pathways. Although communication is incredibly important to the functioning of a system, it is a common source of error. It is also an effective leverage point, as creating change in this aspect is relatively inexpensive and uncomplicated when compared to other leverage points (Meadows, n.d.). While I recognize that I cannot create immediate trust and communication between communities, physicians, and patients, I can help spark this change by increasing a limited range of communication in the present. I aimed to implement more communication between communities of patients and medical technology companies and clinics through encouraging direct, one-on-one communication between attendees and representatives of a multitude of companies, organizations, and clinics dedicated to T1D care. I also aimed to improve communication between the physician, or the general provider, and the patient through providing opportunities to communicate both directly one-on-one and indirectly through a Q&A with medical professionals. Additionally, through incorporating community building time, opinions and experiences were shared that not only helped build community, but also provided feedback for companies. An emphasis was placed on education about how to access and utilize medical resources so that the connection, both to resources and between the patient and the provider, would not be lost. Together, this helped establish an increase in trust and familiarity between patients and providers, and established communication by teaching patients to communicate to providers and showing providers the benefit of listening to and communicating with patients. Since Meadows (n.d.) describes communication as "... popular with the masses, unpopular with the powers that be, and effective,..." motivating the establishment of this communication network is incredibly important. Through communication, education, and sharing information between clinics and supply companies, underserved urban populations, and rural populations, perhaps over time an extra emphasis will be placed on the maldistribution of resources and the medical neglect felt in these communities.

I recognize that even though many of these interventions are aimed at creating fundamental change, in reality they are creating immediate changes for families more than large-scale system change. It is important to remember that changes take time and experiences delays. At present, the event is creating immediate change for families while building relationships between communities and the larger organizations of the system so that the system can evolve and change slowly over time. Families are learning what resources they need and gaining education as to the utilization of health care, while communicating with leaders of the system. Leaders of the system are receiving a new communication line of feedback from customers and communities, while building connections with communities they do not serve. Time is necessary

to form connections, build trust, reallocate resources, and see change in health, which can be divided into immediate health changes, life-time health changes, and intergenerational health changes. I also recognize that KDFD does not address all aspects of the disparity associated with pediatric T1D in Kentucky, such as geographic access limitations and transportation limitations. While it is not feasible to address all of these aspects at once, unaddressed aspects will be especially considered in future iterations of this event to create improvements and serve more people. Plus, Meadows references that slow change can be more effective than fast change as it ensures the participating parties have the resources to stay in pace with the changes so as not to fall behind and cause chaos (Meadows, n.d.).

To create Kentucky Diabetes Family Day, I adapted a phase-based event planning schedule for large-scale events into my personal procedure. The phase-based event planning schedule that I followed was LinkedIn's "5 Phases of Event Management for Success," which incorporates phases based on research, design, planning, coordination, and evaluation (Ballesteros, 2016). I developed the phases of my procedure based on these phases of successful events. I utilized a background research phase, a planning phase, a coordination phase, a preparation phase, and an evaluation phase. Along with these phases, I focused on consistent advertising.

Procedure

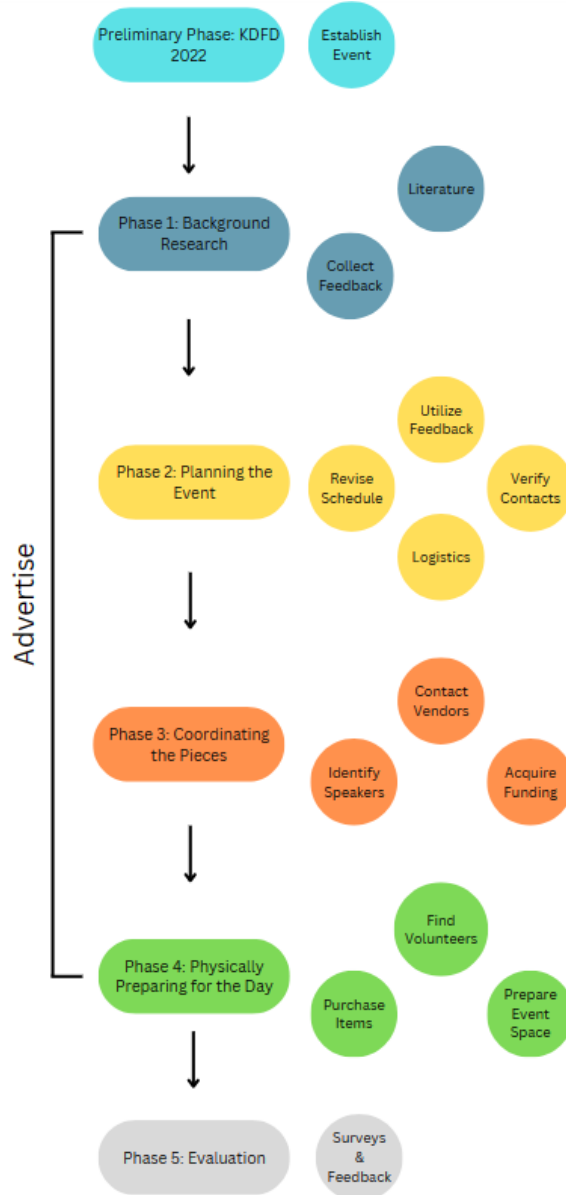


Figure 10. Schematic of the phase-based event planning process adapted for this event. Ovals represent the phases, while circles represent the general tasks per phase.

Preliminary Phase – Kentucky Diabetes Family Day 2022

In this phase, I hosted the inaugural KDFD during April of 2022. I detailed my methods of event planning and coordination as well as any feedback I received after the event. I held a post-event survey to be used in the planning KDFD 2023. I also kept an organized database of all relevant contacts, budget references, grant applications, and advertisement material.

Phase 1 – Background Research to Prepare for Planning KDFD 2023

During this phase, I conducted background research on the needs of families in rural and underserved areas of Kentucky. For this, I used both a literature review and a review of the surveys and feedback evaluating the effectiveness of KDFD 2022. I also investigated advertisement barriers and challenges to equity across Kentucky to identify new ways to advertise to and communicate with rural and urban underserved communities across Kentucky.

Phase 2 – Planning the Event

During this phase, I planned the schedule of the sessions that comprise the event and event logistics such as the budget and location. I compared the feedback from post-event surveys of KDFD 2022, feedback given to me directly by vendors and participants, and my personal observations of the event to revise the schedule. This allowed me to determine which aspects were beneficial and appreciated and which were unnecessary so that I could alter the plan to enhance the experience for participants. With this information, I rearranged my schedule. Since the guest speakers ran over time last year and families benefitted from them, I increased the amount of time for guest speakers. I noticed that some families left after lunch last year, missing what was considered one of the most valuable aspects of the event: the T1D panel. This seemed to be due to the long lunch break and the length of events occurring after lunch. So, I moved the parent-child break out time to the morning half of the event before lunch and shortened lunch time to thirty minutes. While kids loved the breakout time, parents found it less beneficial. So, I shortened the amount of time spent on this and have recruited certified diabetes educators to help with the conversations in the parent room. Guest speakers will also help with this, adding physicians and a dietitian to this mix. Thus, I enriched the adult room to make it more beneficial. Finally, I only left the T1D panel after lunch so that people would be more motivated to stay after lunch for the entire event.

I also reviewed the guest speakers and their speaking topics to determine what type of speakers and information the families would like to hear in KDFD 2023. Families enjoyed the topics, and wanted more of the same. So, I again focused on helpful practical diabetes advice that may be different than what you would get at a doctor's office. I also tried to host a variety of speakers from both clinics again, but that was not as feasible this year due to speaker availability. However, both clinics will have vendor booths again this year, so there will be opportunities to interact with both groups. Finally, I reviewed general suggestions and requests from attendees. One important request I received was the addition of a sensory-recovery quiet zone, which I incorporated into the event this year.

Next, I reviewed my reference material from KDFD 2022. I updated and verified all contacts for vendors, advertisers, and pediatric endocrinology clinics. In addition, I identified more participants and advertisers for KDFD 2023.

During this phase, I also coordinated a venue, using my reflection of KDFD 2022 to guide this process. Last year, our venue was a public building that other groups and people were utilizing, including tour groups. The vendors were also on a separate floor from the participants, and the kid's room was a good distance from the main room. This was not ideal. This year, I chose the Lewis Honors College and booked the entire building to prevent separation and interruption.

I also created a new budget and itemized list of all necessary items. When doing this, I took inventory of left-over material to ensure I did not waste funding or already purchased items. I identified grants to which I could apply to receive funding, and devised sponsorship opportunities for interested vendors. I also planned a fiscal agent for sponsorships outside of the university, as I did not have a bank account for the event, and a mode of using those funds.

Finally, during this phase I created new promotional material and began advertising. I translated the new promotional material to Spanish so that I could include the Spanish-speaking population in Kentucky as well.

Phase 3 – Coordinating the Pieces

During this phase, I contacted medical supply companies, T1D support organizations, and pediatric endocrinology clinics to coordinate vendors and guest speakers. I contacted advertisers to help disseminate information in different communities via different modes as well. For example, advertisers sent out information by email to school systems, through newsletters, by physical posters in clinics, and by personally bringing the information to communities in eastern Kentucky.

In addition to contacting vendors, advertisers, and clinics, I identified guest speakers and their speaking topics, as well as the T1D panel. I also attempted to contact a special guest speaker, or an inspiring person with T1D to come speak with the families.

Additionally, I received funding during this time. I applied for the University of Kentucky Student Government Association Service Grant and was awarded \$1000 for the supplies for my event. I also presented the opportunity to sponsor either breakfast or lunch to vendors. ProventionBio is sponsoring lunch with \$800 while Xeris Pharmaceuticals is sponsoring breakfast and low blood glucose supplies with \$750.

Phase 4 – Physically Preparing for the Day

In this phase, I located the necessary items, while the Lewis Honors College purchased them on behalf of me. I also ordered and purchased food and low blood glucose supplies for the event. I designed posters, a banner, and paper items such as the BINGO card and used RICOH services to have them printed. I also created the slideshow used during the event and coordinated with guest speakers so that I could embed their slides into the slideshow. Finally, I created

volunteer roles and recruited volunteers for the day of the event. These volunteers came from student organizations and Camp Hendon.

This phase also extended to include the preparation for the day. The night before and morning of, we decorated the venue, set up the rooms, prepared the technology, and prepared for vendor booths.

Phase 5 – Evaluation

I will create an anonymous survey to send to the families and professional participants in attendance to evaluate the effectiveness of the event.

Multi-Phase Focus – Advertise

I advertised on social media through the KDFD Instagram and Facebook, as well as maintained the website. I regularly posted introductions and spotlights of guest speakers, vendors, panel members, and opportunities. I communicated across the state with school superintendents, principals, and school nurses. Plus, organizations helped me advertise. Vendors helped share the information on social media, a superintendent sent the information out to all the superintendents in the state multiple times, JDRF sent the information in their newsletter, Camp Hendon informed their families via email and social media, Barnstable Brown Diabetes Center advertised on their social media and in office, and ProventionBio physically took the information with them to eastern Kentucky as they traveled through for work. Advertising occurred throughout phases two through four, and I continued to revise my advertisement strategies and search for more advertising mediums.

Results

On Saturday, April 16, 2023, I hosted the second Kentucky Diabetes Family Day at the University of Kentucky Lewis Honors College. Of the 80 people who signed up, 43 attended and 3 signed up at the door. Of those 43 attendees, 24 were adults/guardians, 11 were elementary-aged children, 4 were middle school-aged children, and 1 was a high school-aged child. A survey has been sent to the families to request feedback on the event, but only a few responses have been received at this time.

Throughout the event, families heard from guest speakers, broke out into age-group discussions for community building, and interacted with a Q&A panel of people with T1D (Table 2). I adopted a flexible schedule approach during the event in order to allocate time appropriately based on need and engagement. To allow for this, I built extra time into the opening and closing sessions and advertised the event as running from 10AM-2PM rather than the actual predicted end time without delays or interruptions. With this flexibility, I used the “Opening” time to wait for people running late from long travels, getting lost, or getting caught in traffic since races at Keeneland, a University of Kentucky Softball game, and a local race were backing up traffic on the morning of the event.

Table 2. Schedule for KDFD. Times noted in black are the original scheduled times, while times noted in red are the estimated time changes made during the event with the flexible schedule. With extra time built into both the opening and the closing sessions, time changes were able to be made with minimal effect on the timing of the entire event.

8:30 – 10:00 AM → 8:30 – 10:15 AM	Check-In & Vendor Visitation
10:00 – 10:20 AM → 10:15 – 10:20 AM	Opening
10:20 – 11:20 AM → 10:20 – 11:45	Medical Presentations + Q&A
11:20 – 12:00 PM → 11:45 – 12:15 PM	Age Group Events + Vendor Visitation
12:00 – 12:30 PM → 12:15 – 12:45 PM	Catered Lunch
12:30 – 1:15 PM → 12:45 – 1:30 PM	Panel with T1D
1:15 – 1:35 PM → 1:30 – 1:45 PM	Giveaway & Closing

During the “Medical Presentations + Q&A,” parents interacted with speakers, paid attention to presentations, and took notes. Families felt comfortable speaking up and asked questions openly. The Medical Q&A was so popular that I rearranged the schedule to take out about 10 minutes from the Age Group Events and push back lunch by about 15 minutes to include all of the events without diminishing the value of the incredibly engaging conversation. Eventually, I had to cut off the questions to continue with the revised event schedule.

During the Age Group Events, parents and kids both engaged in active conversation. In the children’s room, the kids made a craft, this year a decorative candy box to hold candy for treating low blood glucose, while getting to know each other and discussing T1D related ideas. They talked consistently during the time, building community with other kids with T1D. Similarly, in the parents’ room, the parents engaged in a group discussion with help from the medical guest speakers, adults with T1D experience, and a licensed social worker. This conversation in part continued the Q&A from earlier, while also becoming more focused on themes important for parents of a kid with a new T1D diagnosis. Through this, parents also built community with other parents of kids with T1D.

Plus, throughout the event there was frequent vendor interaction, especially during lunch and before the event began. The vendors were in close proximity to the event room the entire day, and so were easily accessible to attendees. Also, kids were eager to fill out their vendor BINGO card to be entered in to win prizes, and so were motivated and excited to visit the vendors. Thus, the vendors experienced high traffic and frequent visitation.

The Panel with T1D was successful as well. This year, I limited the panel responses to three responses per question with exception to answers not previously mentioned in order to limit repetitive statements and to answer more questions. Last year, families were uncomfortable asking questions and used an anonymous form to ask many questions. This year, the anonymous form was not used by anyone. Everyone felt comfortable speaking and asking questions. This led to engaging conversation in a community space.

Feedback on the day of the event indicated that the event was successful and helpful for families. Multiple parents approached me to thank me for hosting the event, telling me that it was very beneficial for their families. Most of the vendors and physicians also approached me to express their praise of the event and its success as well, and their eagerness for future events. Guest speakers also indicated willingness to help continue the event in future years. While I am waiting for feedback from families at this time, feedback from the event indicates that those families in attendance received help.

Conclusion

Although Kentucky Diabetes Family Day 2023 was helpful for the families in attendance, take-aways can improve future events. This year, I implemented a sensory friendly recovery room at the request of a participant. Based on feedback, this was helpful as a safe-recovery space for participants who were overwhelmed by people or easily overstimulated. This is an idea that I plan to continue implementing and researching to make as beneficial as possible for as many people as possible. Admittedly, this was something that I personally have little experience with, and so I plan to continue learning more about this particular accommodation to make the event as accessible as possible. Similarly, the medical Q&A after the medical presentations was a suggestion by Dr. Jackson Smith. This was a big hit at the event, with many families feeling comfortable asking questions. These questions sparked a long conversation that added great value to the event. I plan to continue integrating this into the schedule with appropriate time for people to ask ample questions. Finally, similar to last year, I found that people left after lunch despite a revised schedule reducing the number of events after lunch to just the Panel with T1D. In the future, I will consider moving lunch to last, using it to conclude the event with final vendor visitation and community building time. These three key takeaways will help shape future events.

In conclusion, health disparities relating to insufficiencies in the interconnections comprising the Kentucky healthcare system are substantially affecting the lives of many Kentuckians. However, it is practical and possible to mitigate and resolve these disparities through utilizing a systems-based model. Through identifying key interconnections and leverage points of a system, your personal limitations in altering those key points, and your realistic abilities to alter those key points with your available skills and resources, you can create real, dramatic change to a seemingly unchangeable system.

In this thesis, I modeled this systems-based change by characterizing the key interconnections of the healthcare system driving this disparity, identifying key changeable leverage points of pediatric T1D health care in Kentucky, and by addressing those leverage points aspects through hosting a medical event. Specifically, I addressed leverage points relating to the socioeconomic needs of individual families receiving T1D care and the structure of the pathways characterizing resource allocation and communication through hosting a state-wide, free medical event. This event connected families of kids newly diagnosed with T1D with medical resources and community to which they otherwise would not have access, thus

addressing those leverage points to implement change to both individual families and into communities. This event fails to overcome every barrier to medicine, such as the transportation barrier felt by people who must travel to attend the event. While I will continue to try to overcome more and more barriers to this resource every year, I recognize that I cannot feasibly overcome them all. However, my efforts to create change and overcome the barriers that I can feasibly overcome with the resources available to me begin to create change for individual families and to spark systematic change that will occur over time.

It is important to remember that change takes time. While I am reaching a select number of families directly at the event, the change to the communities will come with time and repeat exposure, communication, and connection. Limitations and resources may restrict the amount of change that is possible at a given time. But, with time and persistence, the effect on the system can grow to be meaningful in a widespread manner. Change does not have to be costly. Kentucky Diabetes Family Day 2023, in total, cost less than \$2,500. To put this into perspective, that is less than the cost of many popular designer purses, less than the unit price of most individual insulin pumps, less than the average out-of-pocket cost of having T1D, and much less than the average cost of one person having diabetes for a year. Through creative efforts, we can create change in people's lives and in systems in a cost-effective and influential way.

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