LAYING THE FOUNDATION: PAVING THE PATH TO WELLNESS

The Children’s WELLNESS EXPERIENCE LAB

The Business Innovation Factory & Children’s Medical Center
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Today, most people would agree that health is more than living without sickness,
and how we get there is more than simply eating right, exercising regularly, and keeping up with doctor’s appointments.
But for single mothers struggling to make ends meet, and the 12 year old girls who just want to fit in...
where does “health” manifest itself in their day-to-day lives?
No regrets it's away of life
What if people were personally connected to their desired futures, inspired and given permission to think beyond today’s constraints, and surrounded by a community of guidance and support?
What if the path to wellness was approached as a journey towards “wholeness”? 
Could this journey inspire persistent, healthy behavioral changes within a family? A community? Across a nation?
INTRODUCTION TO THE PROJECT

Children’s Medical Center in Dallas is dedicated to serving the children in the five counties that make up North Texas. Dallas exhibits some of the worst health indicators in the country—in particular, the high rates of chronic conditions, such as asthma, obesity, and diabetes. This results in increased visits to the emergency department, increased morbidity, and a lower life expectancy.

Children’s Medical Center is seeking new ways to serve these children and their families. This “new way” requires transformative, sustainable models that move away from the focus on “sick care” to a broader focus on “well care.”

In July 2012, BIF and Children’s launched a partnership to design these new models.

At the Business Innovation Factory (BIF), we believe that these models are the product of good human centered designed. BIF starts with a strong understanding of how children and their families experience health care within the system as well as their everyday lives. What are their beliefs, attitudes, and values that influence their experience?

This study serves as a research foundation—providing insights about the patient experience that inspire new possibilities, enabling us to improve the performance of the existing models, and helping us design new models of care.
RESEARCH METHODOLOGY

Between November 2012 and January 2013, the BIF team set out to capture the experience of families who use Children’s Medical Center. Our objectives were three-fold:

- Gather a broad understanding of the values, attitudes, beliefs, and motivations that guide their actions as it relates to health and wellness
- Understand specifically why and when they use medical resources (such as the emergency department, clinics, and primary care facilities)
- Develop deep insights about the chronic condition experience - specifically, understanding the experience of patients with asthma

PARTICIPANTS

Participants in this study included:

- Patients and their families from South and West Dallas, communities with the highest referral rates to the emergency department and with low wellness characteristics
- Patients struggling with chronic conditions, with a strong focus on asthma
- Families who heavily use the emergency department
- Patients from South and West Dallas who are successfully overcoming the hurdles of their conditions (i.e., positive deviants)
We approached this project in three phases:

1. Self Documentation
2. Field Research
3. Analysis, synthesis, and Ideation

Through self-documentation, we wanted to get at two elements of the patient experience. The first is contextual – we wanted to understand where families seek medical information and services and how they envision the resources available in their communities. The second element is emotional – we wanted to understand how patients understand their experience.

To both these ends, we used a mix of activities, which included journaling, mapping, and collaging to increase patient’s awareness of, and reflection, on their current behaviors, perceptions and experiences.
Through field research, we used several methods to capture data:

*In-Home Interviews*
We used interviews with children and their parents as the primary method of understanding the health and wellness experience. Using a semi-structured interview guide, we spoke to 21 families to uncover their attitudes, beliefs, and stories across a broad range of topics. These topics included conversations around the children’s chronic condition, their experiences within the healthcare system, as well as a deeper understanding of the aspects of their lives that contributes, or frustrates, their overall health and wellness.

*Community WriteBoards*
In order to engage the broader community in the discussion about health and wellness, we strategically placed eight posters in areas where residents could contribute thoughts and ideas about what makes a healthy community. We posed new questions every two weeks to facilitate the conversation.

*Group Sessions with Children*
To capture the experience of children, away from their parents, we organized two group sessions in community centers. In one session, we facilitated conversations with a younger age group (5-12), while the second session engaged an older age group (13-16) to uncover the differences in attitudes and beliefs around health and wellness as children progress in their development.

With these stories and observations under our belt, we moved into analysis, synthesis, and ideation. In analysis, we organized our findings – both through narrative and visuals. We broke apart the problem in a number of ways to understand it better. In synthesis, we looked for the patterns in the data. We searched for insights in the patients’ experiences. Finally, in ideation, we combined and recombined our findings to generate a new set of design principles and an illustrative set of opportunity areas that can serve as a launch pad for better mapping our current offerings to the needs of patients, aligning our diverse, and often isolated programs, efforts to better serve patients, and imagining wholly new models and solutions.
ELEMENTS OF WELLNESS

The families living in South and West Dallas are striving for a better life. In our study, we wondered what role health and wellness played in this “better life.” We wanted to understand the values and beliefs that families nurtured, and how they transferred and developed these healthy mindsets from one generation to the next.

The stories that the parents and children shared with us begin to crack open the complexity of their lives, the factors that are working with them and motivating them towards wellness, and the factors that are working against them in their attainment of basic health goals. If we look beyond the generic view of health as “eating fruit and vegetables, exercising regularly, and keeping up with doctor’s visits”, we can see that the notion of health and wellness for these families isn’t so simple - but rather multidimensional.

The experiences of the families culminated in five insights around health and wellness. A complex puzzle of human factors, each insight serves as a specific component of that puzzle. Together, the insights become the Elements of Wellness. They range from internal mindsets to external factors, and all interconnect with each other.

Furthermore, within each element, there is a spectrum of behaviors. On the one end, farthest away from wellness, we see many families that struggle to meet the demands of their families’ health needs. And on the other end, closer to wellness, are the beliefs and mindsets demonstrated by those who have worked around the system and exhibit positive health outlooks, where they understand the value of being healthy and take action to better their health and wellness. It is within this range of behaviors that we see possibilities for leading patients towards wellness and find inspiration for new ways of thinking.
“We know what we’ve got to do. We’ve got to get back to the house to make sure [our kids] have what they need. It’s part of being a parent. You want that time away but you know that that’s a clock that you never punch out, you never punch in. It’s just constant.”
- Mark, father
BALANCED OUTLOOK

For families in South and West Dallas, life is a struggle to constantly optimize resources - time, energy, and money - and to mitigate crises.

Other factors most often related to poverty, such as being a single parent, working multiple jobs, chronic conditions, exacerbate this struggle.

Within this reality, we found that families possess one of two outlooks that fundamentally shape their decision making and behaviors.

On the one hand, families with a reactive mindset manage life from one activity to another, one crisis to another, and lack the foresight to reflect and plan. This has a number of repercussions.

It becomes a positive feedback loop with negative consequences. With stolen moments of respite, parents with a reactive mindset choose to escape reality, e.g. watching TV or taking the weekend to themselves. While these mental breaks are necessary, it is a lost opportunity to better prepare for and manage the chaos around them.

Without this reflection, parents react to each emerging crisis based on convenience and ability -- what will solve the problem in the quickest and easiest way. This short-term, “quick fix” mindset is pervasive and influences how they care for themselves and their families.

“Right now since my kids are little, I want to spend time with them. Even if we don't have a lot of money, I want to give them quality time. I wish I could give them a different way of life, but at this time it’s not possible. Sometimes I put things on a scale - what will be better, to have money or to have sick kids - and I’d rather not have any money.”

- Graciela, mother
It is easier and faster to care for the symptoms rather than look for the root of the problem. For instance, parents may take their children to the emergency department rather than the primary care practice since they feel they can procure treatment quickly - without planning, waiting, or lab visits.

Families with a reactive mindset also struggle to make long-term lifestyle changes to address root problems. For instance, imagine a child suffering from asthma attacks due to moldy air in a rented apartment. For this family, asthma medication is easier (and perhaps less risky) than advocating for themselves with housing management.

Because parents are striving for a better life for their children, they make tradeoffs - sacrificing their own needs for those of their children. For instance, parents may give up their aspiration of getting a degree in order to spend more time with their children, or they might neglect their own health and wellbeing. In both cases, parents are sabotaging their long term goals for short term fixes.

On the other hand, parents with a proactive mindset are able see a longer term horizon, and understand the implications of short term decisions. Here, parents will use personal time to reflect on their experiences, often re-prioritizing and developing solutions for the bigger issues at hand.

Parents with a proactive mindset focus on a longer horizon and see how decisions affect an entire family’s well being. For example, a single mother may spend hours away from her children while she works and pursues an advanced degree, but she will sacrifice the time because she understands the positive impact this will have on her children.
This proactive mindset also generates preventative care, particularly in light of emerging issues. For instance, a mother who noticed her daughter gaining weight contacted a nutritionist to help her daughter “get her health back in line.”

Ultimately, families with a proactive mindset are better able to garner and utilize resources. Through this outlook, they try to create positive sum scenarios for the family.

“It’s nerve-wracking to think ahead before our kids do. I’m always making sure or wondering if I change this in their life, is this something they can use in the future. Is it something that they can use for their children’s future.”

- Katrina, mother
“I supervise him to make sure he takes his controller medicine every day. I don’t do it for him, because I want him to learn how to do it on his own. I try not to limit his activity because I’m afraid... the doctor said don’t do that, just give him the controller medicine and inhaler medicine and if you know he is going to be doing some extra activity, just let him go ahead and use his inhaler before the activity, because they don’t want him to get into a mindset that he can’t do something because of asthma.”

- Sonia, mother
PERSONAL POWER

Power is often defined as the ability to influence other’s behaviors. It also pertains to an individual’s own behaviors. This is a constant struggle for any parent and child combination and, as we saw with families, it has significant ramifications for developing and sustaining healthy behaviors.

Here, the two ends of the spectrum are protective and exploratory.

In a protective mindset, parents attempt to limit exposure to stress. They withhold certain responsibilities and key information from their children in honor of childhood. This leaves children with limited, to no understanding about their health or how to provide self-care. This mindset reduces children’s resilience and capacity, and can lead to endangerment.

Parents with a protective mindset will also limit their children’s exposure to certain people, environments, or behaviors -- whether they are real or perceived threats. This provides parents with a sense of control over situations in which they feel vulnerable.

“If they start running outside, just a little bit, they’ll start coughing big time. That’s why I tell them: don’t run at all. I keep jackets on them. Other people tell me ‘No, girl, you need to take that off of them,’ but I’m like, ‘You’re not going to stay at home with them. You’re not going to take them to the doctor. I know my kids. I know my kids better than you. You’re not here all the time, it’s me.’”
- Adrienne, mother
Ultimately, limiting a child’s sense of his own ability can perpetuate a culture of dependency or over-reliance on parents to guide health outcomes, stunting children’s own self-efficacy. This can also lead to resignation. This not only affects their motivation to stay healthy, it also leads to depression and related conditions.

On the other end of the spectrum, parents seek to incorporate a more exploratory approach, exploring the boundaries of their health and well-being through an understanding of both strengths and vulnerabilities.

This plays out on two dimensions - how they care for themselves and how they enable their children to care for themselves. These parents give their children increasing autonomy, empowering them to overcome adversities.

Rather than withholding information and responsibilities, parents will trust their children to take ownership for their own health. This trust may come as a result of a parent’s beliefs (i.e., “I have faith that things will work out in the end”), or confidence in their children’s maturity to make good decisions (i.e., through their role in the family - needing to be a role model or additional caregiver to younger siblings). Either way, this ownership allows children to build a sense of accountability over their decisions as well as a sense of pride. They begin to see the link between the choices they make and their health outcomes, thus learning from their successes or failures.

Parents and children with an exploratory mindset don’t resign themselves to their circumstances.
They believe there is a better way, and seek out information to find alternatives to overcome their adversities. For instance, we spoke with an asthmatic boy from a very active family. It was unacceptable that the diagnosis would limit his options, and the family sought different treatment options -- eventually finding a doctor who wouldn’t just control his asthma but seek ways to overcome it.

An explorative mindset provides both parents and children with a sense of personal power. Parents encourage their children to manage their condition and enhance their quality of life, while children better understand the link between their behaviors and the outcomes. While children typically model their behaviors after their parents, there are times when parents have a protection mindset and children have an exploration mindset. This is deeply influenced by a child’s sense of self - they know who they are, what they are good at, and who they want to become. They are able to break away from the fear-based mindset of their parents and seek to gain more autonomy over their health outcomes.

“We felt like that the biggest thing we could do is make him be more fit by getting out there and exercising, and not just taking it... you know the doctors are there, but you’re doing something as a parent being proactive, seeing other methods. I say I like doctors information, but sometimes I guess the thing in me to go against the norm, and just go and try and see if it’s going to work... If we would have kept going with what the doctor said he wouldn’t have never been able to play a lot of activities without stopping every few minutes [because of his asthma]. They’re active kids so we didn’t want to tell them, ‘No. they can’t do this.’”
- Tara, mother
“It is important to be a leader because you can do the right things while others are doing the wrong things.”
- Jacob, 12 years old
SENSE OF SELF

A child’s sense of self provides a foundation for who they are, who they want to be, and life priorities. Someone’s sense of self originates from experiences, and is reinforced (positively and negatively) through relationships with significant others - parents, siblings, peers, and others within a personal network. In these relationships, children begin to build values, priorities, and personal aspirations - all of which are ultimately internalized into their sense of self.

When their sense of self is strong - comprehensive, consistent, and meaningful - it helps children make more balanced decisions, gives them motivation for taking action, and builds resilience. But when their sense of self is unstable, they are more easily swayed by external factors and less consistent in their behaviors, leaving them vulnerable to negative influences.

These two ends of the spectrum - stable and unstable - have consequences for how a child values their health and their ability to maintain a healthy regimen.

A child’s sense of self is starts with intimate relationships, and the degree or trust, reliability, and security embedded in these relationships. For many families, providing this reliability is difficult. With hectic schedules and constant crises, there are rare moments when the whole family is together and able to share quality time. When parents and children are not able to bond over experiences and share values, beliefs, and attitudes, children are left searching for those important sensibilities elsewhere.

“The doctors have posters about [asthma] and I’ll just sit there while we’re waiting and read them, but to me it’s something I'll have to probably live with for the rest of my life so I really don’t tend to take it too serious... I try to work out but I can’t because of my asthma. It’s just something I have to deal with.”

- Jasmine, 14 years old
When families do spend time together, health as a value rarely becomes a prioritized part of the conversation. It lacks tangibility and immediacy of return. There are other values - e.g. achieving in school - that are more relevant to a positive future. Many times, both parents and children acknowledge that maintaining a healthy lifestyle may be important, but struggle to see the direct benefit it provides. Without consistently reinforced health habits and values, it is difficult for children to internalize the value of making healthy choices.

Children are constantly moving through different environments, from home to school to community centers to their grandparent’s house. Not all of these environments reinforce positive or healthy beliefs, values, or behaviors. Children who haven’t built a stable sense of self are more susceptible to negative influences. While a child may exhibit healthy behaviors at home, such as eating balanced meals, her “unhealthy side” may come out when she is outside of the house, such as at her grandparent’s house or with friends.

Children also look towards their peer networks to develop a sense of themselves. By comparing themselves to others, they evaluate their strengths and weaknesses as well as examine their own abilities and opinions. Yet many times, children with chronic conditions see themselves as “different” from others. Asthmatic children will focus on their inability to run as fast or as far as others. In an attempt to be “normal”, many children will “test their limits.” Those that have pushed themselves too far and experienced a negative outcome - such as an asthma attack - see that as a solid limitation. This can lead to resignation, where asthma defines who they are and what they are able to achieve.

On the other end of the spectrum, many families highlighted various values around wellness that were important to them, such as honesty, trust, togetherness, and safety. Parent’s who value health as an important part of who they are strive to teach it to their kids. In this situation, healthy habits are transferred between generations.

Children with a stable sense of self develop identities that relate to their health and abilities, e.g. “I’m the best player on my basketball team because I’m fast and shoot well.” This identity pulls them into the future as well, e.g. “I want to become a star athlete to help support my family.”
and make them proud.” From here, they can more easily see the role that health and wellness plays in their lives. This becomes motivation for maintaining healthy behaviors across different environments.

When children with a strong sense of self and a chronic condition compare themselves to their peers, they use the comparison as motivation to “be normal”. In the case of asthma, they will test their limits but they don’t let failures determine their fate. Rather than feeling limited by an outcome, they continue to test their abilities. Similarly, in the case of families that have multiple members with the same chronic conditions, those with a strong sense of self view the diagnosis as a result of their family member’s health decisions/behaviors and use them as an example of what not to do. Ultimately, they don’t allow their asthma to define who they are and who they can be.

“If you don’t do this right the first time, you’ll end up doing it a second time. My mom’s ex-husband, he never finished high school. I saw the way he acted. He was lazy. You can’t really get nothing done if you aren’t active, so I learned from what he was doing. All the things that he did wrong, I tried to make sure that I didn’t do it the way he did it. I made sure I stayed focused in school. I didn’t worry about girls. I worked hard and it all worked out.”

- Justin, 14 years old
“[My uncle] took me with him to the gym everyday - we would run. At home, my aunt would cook healthy food - had vegetables with every meal. We were doing the same stuff we were doing here, but better and healthier - they were stricter. If we did good, he would treat us to a movie or go to the mall. He would try to steer us right and not let us hang out with the wrong crowd.”

- John, 16 years old
SYSTEM OF SUPPORT

The first three elements pertain specifically to internal functions. The final two elements pertain to how families influence their external environments.

Parents depend on a diverse support system to provide care for their children, which may include school, after school programs, community centers, and other family members. Support is deeper than a functional requirement; it provides a sense of stability and security. During difficult times, it provides reassurance and peace of mind.

Families with limited support are not only resource constrained, their children also lack access to role models, information, and safe spaces to explore healthy habits beyond the home.

Here, the spectrum of wellness spreads from limited support to strong support.

Children growing up in households with a limited support network are often left alone - with numerous consequences. They are responsible for their own well being, as well as that of siblings. This responsibility can be too much for children. Often, it results in children adopting habits that aren’t conducive to their wellness development, such as watching TV or eating junk food. It further isolates and limits children from building a support network outside of the home or school. Safety concerns in the community exacerbate the situation, as children are often forbidden to venture outside of the household.

For children, this is detrimental on many fronts. It limits exposure to other people and experiences, viewpoints, and behaviors. It creates an isolated perspective of life options and opportunities. For children living in households with unhealthy habits, this can naturally lead to the adoption of similar behaviors.

“I think his worst year with his asthma was his sixth grade year, because we were in the doctor's office at least three times a week, every week. The doctor and I went to his school, because she was like, something is not right. The classrooms were nasty. Dust everywhere. Air conditioners full of dust. And she said, ‘OK, we can't pull him out of school, all we can do is go to the school board and complain and maybe they might do something.’ But the schools, they’re not going to put all that effort into doing that for one child. So when he transitioned to a new school, there was a big difference.”

- Jessica, mother
Isolation can also perpetuate resignation, especially when multiple family members suffer from the same chronic condition. Many parents and children believe that because of their genetic history, chronic conditions are unavoidable. With this mindset, they rarely take steps to prevent conditions or to ensure they are healthy at the onslaught.

A weak support network can also spread unhealthy habits if that support system is not educated and informed about a child’s health goals or if the child has a weak sense of self. Peer pressure and a desire to fit in make children more susceptible to adopting unhealthy behaviors or attitudes.

On the other extreme, families with a strong support network feel supported and their children are exposed to different viewpoints, often providing inspiration and motivation to make different decisions.

A strong support system begins with developing a diverse breadth of resources. By doing so, both parents and children are exposed to alternative perspectives, attitudes, beliefs, and behaviors. These diverse perspectives promote new ways of thinking and behaving, and it serves to enhance children’s development of their sense of self by testing their own perspectives in the real world.

In a diverse network, children are exposed to more positive role models. This gives them the opportunity to see how others live and provide the opportunity to break away from their family’s habits - especially when they are habits detrimental to their wellbeing. For instance, many children see their parents eating poorly. If they develop relationships with others who model healthier behaviors, they use these individuals as motivation for healthy decisions instead.

Additionally, children can benefit from exposure to negative role models. In these cases, children can learn what not to do from seeing people who make bad decisions regarding their health and wellness. For instance, several children with
Nowadays a lot of kids don’t have someone who’s there to keep them off of the streets and get involved in the wrong things. A lot of parents will be working at night, working different hours, different shifts. It’s good to have security, a place, where your children are in good hands and it’s going to be all positive things that they’re doing. Someone out there, a community, that cares about your child as well as you do.”
- Legashia, mother

A strong support network also helps children be accountable to their own health issues. This is especially true for first generation changemakers.

A family with a strong support network will also embrace a child’s doctor as a trusted advisor. For instance, in one story, a girl’s friends “kept watch” over her eating habits, helping her stick to a tough nutritional regimen and avoid weight gain.

For instance, in one story, a girl's friends “kept watch” over her eating habits, helping her stick to a tough nutritional regimen and avoid weight gain.

A family with a strong support network will also embrace a child’s doctor as a trusted advisor. For instance, one teenager dealt with many health problems throughout his life. He ultimately changed his behaviors at the advice of his cardiologist who helped him re-prioritize his life and take steps to bettering his health. He expressed that the doctor knew how to reach him because of their close relationship.

While the strength of the support system itself is telling, it is also important that the network is enabled through the flow of information, which is discussed next.
“Sometimes, I’m the best doctor there is. About 50 years of doing this, you learn to treat this body yourself because the doctor’s guessing, but I know what’s going on with myself... I’ve got 11 grown children and they all healthy as oxen. I’ve seen them through, so I’ve really enjoyed my life. And the doctor didn’t do it, I did it. That’s the way I feel, I did it... Me and Dr. Jesus”

- Arthur, grandfather/adoptive father
I just use [the internet] to try to keep myself informed on different ways care for her. I try to get point of views of different people and stuff like that. I just always use that Google search, so whatever pops up and I just read all of them. I go down the line and see which one sounds the best.”
- Claudia, mother

CONNECTED KNOWLEDGE

The final element rests on the connectedness of knowledge, information, and conversations. The starting point for information flows are the parent and child. The duo are responsible for accessing information about the condition from a variety of sources, interpreting it, making meaning from it, and sharing it with others. If this communication flow goes smoothly, everyone involved in the child’s care is informed and can act accordingly. However, much like the game of Telephone, those flows can be disrupted by a number of factors. Here the spectrum lies between disconnected information flows and connected knowledge.

Many parents cobble together information from many sources in order to best take care of their child. Sources may include personal experience, intuition, information passed on from friends and family, and information from the medical community.

Many parents claim “knowing their child best,” and determine the extremity of an illness from emotional and behavioral symptoms. They focus on “what has worked in the past.” These parents rely on home remedies that have been passed down, often swearing by their effectiveness.

Parents carry with them a set of beliefs and assumptions about children’s health, which influence how they receive and react to the information. When these assumptions are contradicted, parents don’t trust the source or the information, considering it just another input. When this happens at the doctor’s office, the parent and child often walk away with more questions and less trust. We heard several stories about miscommunication around diagnosis, resulting in multiple emergency department visits. One mother thought her daughter was being prescribed medication for headaches, that were were actually antidepressants that led to suicidal tendencies. She now finds it hard to trust doctors.
Disconnected information is further complicated by poor care coordination. When a child has multiple care providers, they can work within silos, not communicating about treatment or care. This can also result in distrust. One doctor prescribed preventative asthma medication for a patient which conflicted with an ADHD medication prescribed by a different doctor. Because of the negative interaction, the boy distrusted his prescriptions and ceased taking the preventative measure.

Further, information becomes additionally disconnected when poorly interpreted. This leads to misperceptions and myths, and can result in risk-averse fear-based mindsets. For example, parents who bring their children to the emergency department during an asthma attack are shown a specific video. In the video, a child dies because a parent was unable to diagnose an asthma attack and get to the emergency department in time. This video generates two different reactions - either it helps parents understand the seriousness of their child’s asthma and the importance of knowing the signs of an attack, or it ends up instilling fear in parents, resulting in them bringing their child straight to the ED no matter what.

Disconnected information is further aggravated when distributed to a child’s multiple caregivers. When misinformation is decentralized, myths get perpetuated. Other times, caregivers are not informed at all about a child’s condition, and are unable to recognize the signs and triggers or implement a treatment plan.

In contrast, there are some families who benefit from connected communication flows. In this case, knowledge about a child’s health is consistent, communicated to a broad support network, and is acted on collectively.

When children and their parents interact with their doctor, it’s a two-way conversation where both the doctor and the parent and child feel heard and understood. Assumptions about the child’s health are surfaced, addressed and clarified. One mother described feeling in control of her son’s asthma because she knows exactly what to do depending on his symptoms and what “stage” he’s in. The information she received from her doctor was synthesized and actionable, and thereby effective.
Where there are knowledge gaps, some parents and children will seek to fill them independently. The need to know the facts for themselves is a great quality for a patient and their caregiver to possess. This curiosity and exploration mindset (as mentioned earlier under Personal Power) is a behavior that should be encouraged, with the child’s caregiver there to ensure accuracy of information.

With the parent and the child at the center of all information flows around the child’s health, and both as the gatekeepers of their own subset of knowledge, it’s vital that the parent and child work together and share necessary information with each other. The more that the parent knows about how a child is doing, and a child knows about their condition, the better they can communicate information to others beyond themselves, ensuring the child receives optimal care.

When distributing information to others who care for the child, open communication and consistency is the key towards a holistic vision for the child’s care across their support system. One mother and her daughter, who has epilepsy, had a meeting at the beginning of each school year with all of her teachers, to consistently and collectively share the necessary information to them about her condition and what to do in case of a seizure. This helps her parents feel confident in her care. Connected communication flows result in trust, a necessary component to have within a child’s support system. The act of sharing information not only forces the caregiver and child to place trust in the hands of others, but it builds trust over time.

It’s important for parents and children to have access to accurate and synthesized information, be able to communicate with each other and their support system, and for everyone involved in the child’s care, including doctors, to share consistent knowledge around the child’s health.

“[Children’s] teaches us how to know when our child is having an asthma attack and how to know the first signs and how to address it to the best of our knowledge. They show you this video of this woman who lost her son to asthma... because she didn’t get him to the hospital in time. I don’t want that to happen. I now know how to attack it head on. My mom or his father will call me, and I’ll tell them what to give him... what stage he’s at and how to address it.”
- Jackie, mother
**DESIGN PRINCIPLES**

At BIF, we believe in human-centered design as a process for understanding the experience of people we seek to serve. We think there is great value in using this insight to iteratively design and experiment with new models. To help move from insight to action, BIF used our insights from the research to develop design principles. These design principles are the building blocks that will define successful patient-centered solutions.

**WHAT FUTURE SOLUTIONS NEED TO DO**

*Personalize the experience.*
People need to feel like they have a stake in their own care process, otherwise they will withdraw. Tap into their sense of self to understand the values and aspirations that are important to them, and work with them to co-create the experience they want to have - thereby giving them the privilege of choice - rather than dictate a “one size fits all” approach.

*Meet families where they are.*
Currently, the decisions made around care rarely take into account the lifestyle and conditions that children and families live in. What may sound easy on paper may not translate well into the reality of the situation. Aim to bridge the gap between what should be done and what can be done by making apparent the implications on their lives - thus, providing them with a more balanced outlook on their decisions.
Honor children’s role in their own development.

Acknowledge that children are going through a process of development, which has an effect on their physical, mental, and emotional capability. Provide them with the personal power to play a role in their health and wellness by encouraging them to test their autonomy and build accountability and resilience, thereby facilitating a strong sense of self and a positive development path.

Facilitate an open and transparent dialogue.

Help create a common language and connected knowledge by unearthing personally held beliefs. Surface assumptions and perceptions about health and chronic conditions to align perspectives. Encourage sharing of experiences between people to bridge isolation, foster trust, and build stronger systems of support.

Build both individual and collective knowledge.

“It takes a village to raise a child”, but currently the “village” isn’t factored into the care process. Encourage the system of support to play a role in children’s wellness outcomes rather than relying on just a small subset of the family to connect their knowledge to others.

Foster sustained engagement.

Health is something rarely thought about outside of the moments when people need to think about it, such as health crises or doctor appointments. Even healthy behaviors tend to fall off if they aren’t reinforced and built into habits. Encourage engagement with their sense of self by providing the motivation to do better and achieve more.
OPPORTUNITIES

The research and insights point to many opportunities for evolving or designing wholly new experiences for improving the health and wellness of our children and their community. Opportunity spaces reframe challenges and needs, in a generative, future-facing way. Each space defines an area where multiple ideas for new solution concepts can be developed.

What follows are five opportunity spaces—potential areas that seek to:

1. Redirect families from using the emergency department as a frequent source of care,
2. Facilitate healthy outcomes for chronic care patients, specifically around asthma care

While the following opportunities are intended to be illustrative, they are by no means exhaustive.

1. How might we facilitate a greater sense of control beyond the emergency department?
2. How might we create more convenient sources of care?
3. How might we make health more tangible for children in order to engage them?
4. How might we inspire, guide and support first generation changemakers?
5. How might we deliver care beyond the child?
How might we...

Facilitate a greater sense of control beyond the Emergency Department?

By giving families access to the right information and knowledge, they can confidently assess and triage their children’s health crises.

CONTEXT

Many families use the emergency department when they feel out of control - when they aren’t sure how serious a health issue is, or when they don’t know what to do or where to go for help. This stems from two problems - not having proper access to information as well as not having relevant or actionable information for them to accurately assess the situation and take the necessary steps to correct it. As a coping strategy, many parents tend to be overprotective and fearful due to their lack of confidence in controlling the condition. In this state, they use the emergency department as a way to assess their children’s health problems - whether it is warranted or not.
From:

• A place of ignorance or misunderstanding about the triggers, signs and symptoms of asthma
• Feeling helpless and powerless to control or impact health crises that come up unexpectedly - especially when they are outside the parent’s supervision
• Using fear of not being in control as motivation to use the emergency department

To:

• Direct access to qualified, meaningful and actionable information that helps families plan for and triage unexpected health crises
• A culture of exploration where both the parent and child learn to recognize signs and determine acuity
• Alleviating worry by transferring consistent knowledge to support system
• Feeling powerful and equipped to accurately assess their child’s health condition
**APPROACH**

To curb this problem, we should put more knowledge into the hands of the families. It begins with making sure they have **access to actionable and consistent information right from the start**. Within the hospital and in the community, we imagine solutions that can provide ongoing education and learning opportunities as well as tools that can better **equip them to quickly and easily triage in moments of crisis**. These solutions should aim to meet families where they are by providing immediate or on-the-fly diagnoses in order to fit in with their hectic lifestyles.

We imagine building both individual and collective knowledge to educate and teach each person that plays a role in the child’s health and wellbeing - including other family members and their support system. By **decentralizing children's health information and care plan**, we can ensure other care providers have the information and ability to follow through. Ultimately, this can put parents’ anxieties at ease when they are away from their children.

In addition, there should be special regard to the communication between children and parents. Rather than relying on “mother’s intuition” (as parents currently do), potential solutions can help children **articulate what they are experiencing**. This helps to diminish miscommunication, misinterpretation or withholding of knowledge, and facilitate quicker action.
We also imagine solutions that can facilitate a sense of control by **providing a safe place to explore the limits of children's chronic conditions.** We want to allow parents to approach the triggers believed to be a health risk, and in doing so encourage self-efficacy and confidence. By facilitating an open and transparent dialogue, we can debunk some of the most common assumptions or misperceptions around chronic conditions. That way, we can not only teach parents and others how to care for children with these conditions, but we also begin to build more accurate interpretations of risk and acuity. By providing them with a more accurate understanding of what children can achieve as well as developing a more exploratory mindset, parents can stop relying on fear- or avoidance-based approaches to care.

In experimenting with this concept, we want to learn more about:

- The tools and technologies that are most accessible to the population
- The form, level, and amount of information that is necessary to provide a clear and actionable plan for health crises
- The partnerships that will help reach and engage children, their parents, and members of their support system for moments of learning
How might we...

Create more convenient sources of care?

By making current resources for care more accessible as well as creating new community-based care touchpoints, we can help steer families towards using care resources that better fit their lifestyle and needs, and away from using the emergency department.

CONTEXT

The emergency department is often the convenient choice for most families. It’s the place people go if a treatment doesn’t work and they need help NOW. It’s where they get everything they need, rather than spending numerous visits to the clinic or pediatrician to have tests done, get the results, and schedule a follow up. In the emergency department, parents know their children’s needs will be taken care of no matter what.

Additionally, they don’t feel connected to the other care available resources, in part because the investment is not reciprocal. At the primary care office, doctors produce a diagnosis after a 15 minute visit, and provide a treatment plan that may or may not fit into the constraints of a family’s lifestyle. When people don’t feel like their needs are being met, they don’t feel engaged, so they go with the option that will use up the least of their resources.
Feeling that the emergency department is the easiest and most convenient source of care
A place of apathy and indifference when it comes to care resources
Basing health decisions solely on the optimization of money and time

Families having the luxury of more flexible options of care that fits their lifestyle
Care providers that are more informed about the community and its families to more effectively meet their needs
A co-created care experience that is aligned to the patient and family’s preferences
**APPROACH**

In addition to helping people more confidently assess health crises, we imagine **increasing the flexibility and availability of non-emergency care options**. This opportunity leans heavily on the design principle of meeting them where they are by offering solutions that better fit into their lifestyle and the environments they frequent. We can accomplish this, first, by making current non-emergency sources of care more available to parents and children. Examples may include extending doctor’s office hours outside of the typical 9am to 5pm to allow working parents a chance to take their children in without having to miss work or school, or create drop-in hours to provide them the option of using these resources when minor crises arise.

Additionally, we imagine solutions that **decentralize and localize care from the hospitals and clinics into the community**. Creating new roles for local care providers can not only help with triaging some of the crises, they can also serve as a trusted information source within the community to spread accurate knowledge - thus, building both individual and collective knowledge. By **establishing community liaisons between the hospital and communities**, Children’s Medical Center can keep the pulse on the trends and issues that are going on at the neighborhood level, thus facilitating an open and transparent dialogue between the hospital and the community.
Finally, in order to help deter emergency department use, we envision a way to incentivize the use of other sources of care. This could happen with physical or financial incentives, or by personalizing the experience. By working with families to co-create the care experience they seek, we can give families more of a choice in their care and more of a stake in the process.

In experimenting with this concept, we want to learn more about:

- Which places or areas of the community will best respond to new touchpoints of care
- What experience families and children are seeking to have with their sources of care
- What options of care people are motivated to use in different circumstances
**How might we...**

**Make health more tangible for children in order to engage them?**

By making future outcomes more tangible and relevant to their lives as well as providing action-oriented goals along the way, we can help children be more accountable for their behaviors around their health - thereby building confidence and resilience in the face of their condition.

**CONTEXT**

Many children admit that they feel at their best when achieving in school - such as getting a good grade on a test or being recognized for an accomplishment. Unfortunately, these tangible achievements don't translate very well into their health and wellness. Due to a disconnect, there is no clear link between their behaviors and their outcomes, since the consequences of their actions usually become apparent in the future, as adults. Because of this, they don’t feel a sense of responsibility or accountability for their behaviors until it’s too late to change. Simply put, there is no tangible accomplishment for staying healthy. Good health is just a neutral, vague, and abstract state of being.
A limited understanding of how their actions now can affect their health later
Health goals that don’t necessarily align with their lifestyle or take into account what motivates them
Uncertainty of how to control or overcome their condition, which can lead to resignation

Helping children become aware of the implications of their behaviors and actions, and seek to become healthy adults
Collaboratively setting short term and long term goals with care provider and support system
Having others hold them accountable to their goals, and play a role in reinforcing and encouraging healthy behaviors
Understanding the ultimate trajectory of their health outlook and building the skills that lead to confidence
**APPROACH**

We want to harness the power of tangibility to make children more engaged with their health. First, potential solutions can help children see their future based on their daily health decisions - whether positive or negative. This can be achieved by personalizing the experience and engaging their sense of self - that is, what is important to them and where they see themselves in the future. That way, we can begin to make healthy goals and outcomes more relevant to their lifestyle and aspirations. By understanding the constraints of their lifestyle and their abilities, we can meet them where they are and design goals and outcomes around those limits. To ensure all parties are aligned, this process should be a collaborative effort between children, parents, and care provider.

We can foster sustained engagement with their goal program by providing incentives for healthy behaviors. These incentives don’t have to be physical or tangible things - rather, self-worth and pride are strong motivational factors for kids. We imagine solutions that tap into both these intrinsic and extrinsic motivations.

Providing frequent feedback loops to let children know how they are doing in real time by tracking behaviors or decisions and giving immediate feedback that reinforces or redirects behavior. Additionally, giving others - particularly, children’s care team - access to this data could give them firsthand information about their actual habits, and facilitate an open and
transparent dialogue by providing guidance accordingly. We want to build both individual and collective knowledge by looping in the child’s broader support system. We can make a child’s goals explicit and shareable and highlight ways that others can help. This gives teachers, grandparents, peers, and others in their support system tools to help children meet their goals.

Ultimately, by making children and others accountable for their health through clear and explicit goal-setting as well as making the link between their decisions and their outcomes more apparent, we are able to better honor children’s role in their own development.

In experimenting with this concept, we want to learn more about:

- What makes actionable, relevant, and motivating goals for children
- The different tools and mediums that children have access to and will engage with
- Creating the right balance between private and public access to children’s actions and behaviors
How might we...

**Inspire, guide, and support first generation changemakers?**

By engaging children who are taking accountability for their health, we can create a self-sustaining movement by connecting them to other changemakers, celebrating their successes, and help them inspire their families and others in the community to adopt healthy habits.

**CONTEXT**

Many families admit that they don’t have the healthiest habits in their homes. Yet, some of those children manage to break away from the habits within their household to develop healthy behaviors and perspectives. Many feel alone in their quest, since they don’t feel they have others to lean on for help, advice, or support. Knowing that this small yet powerful trend exists, how might we harness this to create better outcomes in their households as well as in their communities?
• Limited support system where changemakers feel isolated and alone in their decisions with little support from family and friends
• Limited to no access to others to seek advice and guidance from when breaking the mold
• An uphill battle to sustain their new healthy habits, rather than break them
• Hitting a wall when trying to get family involved in the movement to change

• Harnessing a strong sense of self in current changemakers, and building it up in future changemakers
• One where they feel part of a movement- able to find and connect with a tribe of like-minded individuals who learn from one another through story-sharing
• Healthy behaviors and efforts towards them becomes the new "cool"
• Changemakers are leaders of healthy behavior change within their households and communities
**APPROACH**

As we discuss in our insights, many of the children who were first generation changemakers possessed a strong sense of self - that is, they had a clear vision of who they are, the values that are important to them, and who they want to be in the future. Therefore, potential solutions should harness current changemakers' strong sense of self by acknowledging and encouraging their independence and resilience, while building up future changemakers' sense of self by increasing their autonomy, efficacy and resilience in the face of difficulties - especially when it comes to asthma.

Connecting children to others with similar experiences helps them realize that they aren’t alone, but rather part of a like-minded community where they can share stories, struggles, or provide advice. In this community, we want to facilitate an open and transparent dialogue about asthma by leveraging stories of success and catalyze a movement of positive change through story sharing. We can celebrate children who have learned to control and live with their asthma. We can honor children’s role in his or her own development through solutions that reduce the stigma of the condition and promote the condition in a more positive light. When children instill ideas about what they can do rather than what they can’t, it protects against resignation.

Also, solutions can use pride as a motivation by publicly celebrating their efforts and achievements towards good health. Broadcasting their behaviors to a wider audience can serve to inspire others in the community, by showing alternative options of who they can be. They can be role models for other children who aspire to be healthy. It also provides changemakers with something to work towards, and incentive to stay on track.
Once inspired, potential solutions should provide future changemakers with qualified and personalized guidance and mentorship - applicable to their life and the context of their family. Because each child is unique in terms of motivations, a “one size fits all” strategy has little meaning in their everyday life and makes it difficult to engage in change. Thus by personalizing the experience by understanding their motivations and solving for their struggles, we can help remove the barriers that get in the way of healthy habits, and replace them with feasible healthy habits. We want to work with the child to understand his or her context and allow for guidance to be more relevant and applicable.

In experimenting with this concept, we want to learn more about:

- How to find and engage current changemakers
- How to equip children with the skills to enact behavior change within their family
- The cultural norms, traditions, and family structures that could influence the success of changemakers
- The socio-economic factors that may play a role in the adoption of new behaviors
How might we...

Deliver care beyond the child?

We can play a role in developing lifelong families of wellness that carry through current and future generations, by looking beyond the child and contextualizing care throughout her life.

CONTEXT

Currently, the healthcare system treats children through a limited scope of understanding. Children’s health is tracked and addressed through intermittent appointments, with limited knowledge or understanding of context in which they live - including their family life. This isolates their health from the major influences and experiences of their everyday lives, and provides a limited view of each individual. Additionally, the beliefs, values, attitudes, and habits that exist in households play a huge role in children’s health and wellness. Yet the healthcare system treats the individual outside of the context of the family. Lastly, once children are out of the scope of pediatric medicine - i.e. when they turn 18 - they are let loose, whether or not they have properly learned how to manage their condition and their health.
TRANSFORMATION

From:

- Understanding and treating children through the lens of the limited and episodic visits to the doctor
- Siloing the individual from the familial influences that play a major role in their health and wellness
- Passing the buck on addressing the unhealthy beliefs and habits that are spread within families and over the course of one’s life

To:

- Treating the root causes of issues through the lens of children’s everyday life, in turn preventing more significant issues down the road
- Family-based network of health influences and outcomes
- Lifelong health documentation
- Equipping children to continue healthy habits into adulthood
**APPROACH**

Children are moving between different environments all day long, and being exposed to different social environments, all of which have an impact on their overall wellbeing. When children visit with a doctor in their office, it’s difficult to assess all the influences contributing to a problem. Solutions should aim to help doctors understand the “whole child” including aspects of their life (social, environmental, relational) that may not directly have to do with their health, but impact it greatly. The key becomes working with these factors rather than around them.

We imagine future solutions that meet families where they are by looking beyond the child and incorporate more of a family perspective. By providing care that centers around the family unit, we can view children in the context of their household and uncover patterns of familial beliefs and behaviors that were previously hidden. Facilitating an open and transparent dialogue between members of the family and the care provider could address gaps in knowledge and awareness around the child’s chronic condition as well as health habits. In this solution space we could help whole families become healthier by being partners in wellness, rather than treating each individual separately.

Similarly to contextualizing children’s health through the lens of the family unit, what if children’s health was documented through moments of their everyday life - literally from “the cradle to the grave”? Their health would no longer be limited to the relationship between children and their pediatrician, living on documents that are typically inaccessible to anyone outside of the healthcare system, but rather be a record of their health over a lifetime. We can imagine a “living health document” that stuck with children throughout their life, where
multiple people - not only the doctor - could contribute their experiences that influenced or affected their health. It not only serves to create a history of health moments that could be accessed by those who play a role in children's wellbeing - doctors, parents, teachers, or others. It would help facilitate an open and transparent dialogue around children, thus personalizing the experience to be tailored to their lifestyle and needs.

Lastly, what happens when children “graduate” from Children's care? Is there a way that Children’s can play a role in creating lifelong believers of wellness by equipping their patients with the life skills needed to lead a life of good health. We can imagine potential solutions that provide a learning program that honors children’s role in their development by ensuring that they learned how to care for their condition as well as learned how to navigate the healthcare system and care resources. These potential solutions would provide the relevant knowledge they need to become fully formed adults as they move on from Children’s, and eventually leave behind a legacy, propagating a multi-generational movement of wellness.

In experimenting with this concept, we want to learn more about:

- The conditions needed to bypass current constraints of how care is delivered today to enable care beyond the child
- The appropriate inclusion of “family” that takes into account all the major caregivers in the child’s life outside of the nuclear family
- The current tools and technologies that exist to track health behaviors and experiences
- The method and areas of learning that would best serve children to become lifelong believers of wellness
NEXT STEPS

The notion of health and wellness is multi-dimensional. It is about having a balanced outlook in stressful situations, having a sense of personal power and knowing ourselves, having a trusted network of support in place, and having knowledge to help guide us towards positive outcomes in our lives.

Yet our healthcare system often deals with only one aspect of wellness - ensuring the absence of illness. This one-sided, siloed solution fails to address the complex and interconnected physical, emotional, and mental aspects that facilitate wellness. It also fails to acknowledge the other systems that impact a person’s wellness. It’s not just about the individual; it’s about understanding the other levels of influence, such as the family, the larger community, and the healthcare system as a whole.

The path to wellness began by understanding the crucial elements that help us assess the needs that we address in order to facilitate positive health and wellness outlooks in the people of South and West Dallas. Based on our insights, we identified the characteristics of successful patient-centered models and a number of opportunities that can inspire new ways of approaching the problems at hand.
The question now is, how will we act on this inspiration to create a new model of care that focuses on 'well care' rather than 'sick care'?

What new business models and opportunities can we articulate and frame? What capabilities do we have that can be applied to better serving the patient's needs? What partnerships can be leveraged to help us serve these families? What questions do we have that can be answered through experimentation? What prototypes can we build to help test these hypotheses?

These are the questions critical to accelerating the pace of business model innovation within Children's Medical Center and making business model innovation relevant and accessible.

We look forward to the opportunity to continue on this transformational journey with Children's Medical Center.
ABOUT THE BUSINESS
INNOVATION FACTORY

The Business Innovation Factory (BIF) creates real world laboratories where organizations can design, prototype, and test new models for delivering value. BIF’s mission is to enable business model and system level innovation in areas of high social impact, including healthcare, education, energy, and entrepreneurship.

BIF’s Patient Experience Lab provides an integrated model of design research that directly engages patients in real-world R&D. By understanding their experience within the healthcare system from their point of view, BIF is pioneering a pathway that takes human-centered research and design off the whiteboard and into the real world.

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