One year ago, I designed a prototype for an app and website for caregivers of children with Autism Spectrum Disorder. A distributor in the healthcare industry advised me to copyright the idea, build it, and put in the world for people to use. I hesitated. I knew that I had much to learn about Autism and the daily lives of caregivers. Before I could design an effective tool, I had to better understand the lives of the people who would use it, and I had to work directly with them to craft it.

Why Autism?

I first became interested in Autism because I submitted a design to *Autism Connects*, an international design challenge sponsored by Core77 and Autism Speaks. The challenge asked students to help individuals with Autism Spectrum Disorder (ASD) better connect with the world around them and allow people who do not have ASD to better understand and connect with those who do. Initially, I learned that caregivers of people with ASD manage a lot of information. They constantly schedule appointments, set goals, monitor behavior, diet, and track the progress made by their loved ones over time. One person is not enough to handle all of these challenges, and caregivers—usually parents, relatives, teachers, and therapists often work together to implement care. I knew that design and technology had the potential to make the care process more simple, enjoyable, and efficient. I designed a concept called *WeSync* that would centralize data and help ASD caregivers consistently track and implement care. My design for *WeSync* won the juried prize and the community prize, and I was invited to present it to over 1900 scientists and autism advocates from countries all around the world at the annual International Meeting for Autism Research (IMFAR). Though the design was only a prototype, I received

excellent feedback. I was moved by how many people were excited about the way it looked, functioned, and how it might fit into their daily lives. After IMFAR, I wanted to learn more about the needs of the Autism community in order to improve *WeSync*. I laid out a plan for research and spent my thesis year listening to and working with the Autism community.

Designing a Plan

I aimed to learn as much as I could about Autism, ASD caregivers, and the medical industry. I planned the following strategy:

1. Learn more about Autism

2. Interview experts

3. Interview caregivers

4. Facilitate a card sort

5. Work with a child who has Autism

Understanding Autism

What exactly is Autism anyway? The truth is, nobody really knows. We don't know what causes it, but know that genetics and the environment play a role. Autism is a developmental disability that affects a person's ability to communicate and socialize. The Autism spectrum is wide and can range from mild to severe. Some individuals may be nonverbal, while others may be gifted with words, numbers, and memory. No two cases are ever the same, and the unique nature of each child makes it difficult to plan care. There is no known cure for Autism, but doctors, therapists, teachers, and parents can help

children overcome challenges in order to lead a fulfilling life/lives. In November 2012, *60 Minutes* featured a special on how iPads and technology are changing lives for people with Autism, and I wondered, "Why not for the people who care for them, too?"

Understanding Experts

I began by talking to many of the people whom I met at IMFAR. The first person I called was my main contact, Simon Wallace, PhD, Director of Scientific Development and head of Technology Initiative for Europe Autism Speaks. When I told Simon I wanted to make *WeSync* real, he was excited. He told me, "Communication amongst professionals, and between professionals and families, can be poor at times. *WeSync* would help overcome some of those hurdles." He also explained that making it real would be tricky, because there are many privacy laws that I will need to navigate. He suggested I research laws around the electronic storage of medical information.

This led me to my first question. By law, who can share information and what are they allowed to share? I learned that doctors couldn't share information with others unless the patient or guardian signs a waiver. I learned that health systems could be hacked resulting in a loss of privacy for the patient, and how to implement digital tools is an ongoing debate and challenge in the healthcare industry.

As I spoke with more people, I started to feel overwhelmed. In 1996, a law called HIPAA (Health Insurance Portability and Accountability Act) was introduced. HIPAA contains lots of laws around how health information can and cannot be shared through technology.

My original concept for *WeSync* proposed ideas that are not entirely legal, which made it near impossible to imagine rolling out my initial plan.

I went to New York to speak with Mark Surkin, the CEO of Autism Speaks. He is an advocate for *Hacking Autism*, an initiative whose main goal is to create apps for the Autism by connecting the ASD community with designers and developers. I explained to him why I thought my product idea for *WeSync* wasn't possible. Mark simply said to me, "Instead of focusing on the people who can't talk, what about focusing on the people who can?" Genius! From there, I was able to reframe the design problem. *WeSync* would no longer be about doctors and therapists talking. Now, it was about family, relatives, and teachers. It would focus on the people who consistently surround the child daily, rather than monthly, every three months, or annually. This was a turning point in my process, and once this was clear, I realized that I needed to get out and talk to caregivers.

Understanding Caregivers

I interviewed nearly 40 parents, teachers, and specialists about the challenges of organizing care for a person with Autism. Through these conversations, I learned that caregiving can be as isolating and stressful as it is rewarding, that coordinating care amongst family and professionals can often be a challenge, and that many care plans contain an exhaustive amount of paperwork. One mom whom I interviewed told me, "Scanned storage of test results would be extremely helpful in a tool. Goodbye three-inch binders!" This confirmed her strong desire for a digital tool made just for her. My next step was to figure out what content might be included, and how it might be organized.

Understanding Content

I created a card sort at the suggestion of my thesis advisor, Rob Giampietro. Card sorting is a technique for finding the best way to structure an interface. With the help of a Mom, I created 50 cards with words and phrases that might become content for an app or website for ASD caregivers. Then, potential users were asked to rearrange the cards into groups or clusters and name each of those categories as they see fit. Learning how users view the content, rather than myself, provided valuable input to how a product might be structured. For example, one mom that I met with had two children with ASD; I had never considered that a parent might be organizing care for more than one of their own children.

Understanding the Child

For six months, I volunteered weekly to play with a 4-year old boy who has Autism. We did puzzles, drew pictures, and raced imaginary cars. I had the privilege of trying to see the world from his perspective, and witnessed some of the ups and downs of caring for a kid on the spectrum. There were sad days when he faced the wall crying for reasons that I did not know or understand. Then there were breakthrough days, like the first time he said my name aloud.

I met biweekly to observe his teachers, therapists, parents, and volunteers and began to understand their lives as well. I observed how they communicated with each other. I realized that when they talk, it is less often to compare hard data, like a 24% percent

decrease in whatever. More often, they would share stories or moments about the time they last spent with the child. The moments, good and bad—happy and sad, were something everyone could relate to. I also learned that the most rewarding part of caring for someone is watching them progress, and often these are the moments motivate a caregivers. One teacher told me, "The small but steady steps the child achieves and the improved quality of life for the child and the parents make her job worthwhile."

Design Challenges & Considerations

Throughout my research, design challenges and considerations have been revealed. I've concluded that a digital tool for the ASD community should or might:

-Streamline care amongst people who are ethically able to participate

-Reduce and organize paperwork

-Connect a caregiver with others to help them feel supported

-Simplify information, to make the many facets of care more manageable

-Have the ability to be easily scanned or read

-Be flexible enough to customize, because the specifics of care are unique to each child.

-Be a system that includes emotion and experience, not just data.

What's next?

After a year of observation, conversation, and sharing ideas, I have an improved prototype for *WeSync* shaped directly by people in the Autism community. Throughout this process, I've gained empathy and understanding—a perspective that I couldn't

design without. I've gained a practical understanding of health and privacy laws, a more in depth understanding of Autism, and a much greater understanding of the challenges faced by ASD caregivers. Although this project is far from complete, I am much more equipped than I ever was before. This April, TEDMED acknowledged that caregivers have few tools as support systems and listed defining innovations for them one of the great challenges of Health and Medicine for 2012. Great challenges require more than one person. In the future, I hope to partner with an organization to realize *WeSync*, so that one day, it might improve the lives of ASD caregivers and their loved ones affected by Autism.