A Place at the (Inclusive) Table:

Observations about Inclusivity and the Question of Who is an Engineer

By Mary Martin

The discussion of inclusivity and accessibility is often something that happens in a closed system, where able bodied people discuss how to make things easier for people who have a disability. When written out on paper, it seems silly, like not inviting someone to their own party, but in reality it happens constantly. In order to most effectively meet the needs of people with all abilities it is necessary to include them at the discussion and to recognize their ideas and solutions as more valid than those created by people who do not actively live with the disability they may be designing for. When teams, companies and projects fail to include people with disabilities in the create of solutions that will supposedly make their lives easier, not only does society lose the possible contributions of an entire community of people, but the solutions that are created are often not the most direct way to solve the problem. Inclusivity means not just including the ideas and words of people with disabilities but also recognizing the contributions of disabled designers and engineers themselves.

Background:

During the summer of 2015, I worked on a research team led by Sara Hendren, with two other students from Olin College, Toni Saylor and William Lu. The research team worked on multiple projects in the accessibility and inclusivity design space, including conducting background research for a book proposal that Professor Hendren was starting and working to document and share the work done by a woman named Cindy, who had created a variety of innovative solutions to modify her environment to suit her needs as a person with multiple disabilities.

The team investigated a variety of topics for the book proposal, all focusing around different treatments of disabilities, whether the solutions be medical, architectural or societal. These topics included deafness and the deaf community, post-cancer breast reconstruction and therapy/service animals. By investigating the different ways that people approach creating solutions for issues that people with disabilities encounter in their daily lives, we hoped to document the variety of ways that designers and engineers have attempted, and sometimes had success with, improving the lives of people with disabilities.

The second project that we were working on, with Cindy, was a joint project with Professor Caitrin Lynch. We had the honor to work with Cindy, a woman who had never considered herself a "creative" person until she found herself in a position where the environment around her no longer fit her physical needs. As a result of complications after a heart attack, Cindy's legs below her knees and most of her hands were amputated. This change to her abilities made some daily tasks that had been simple before difficult or impossible to do in the same way as before the accident. To meet her new needs, Cindy started creating "MacGyver-ed" objects and projects to make her life easier. She created a whole range of objects herself, and also worked closely with her prosthetist, Greig, who helped her make

more specialized tools. We spend our time interviewing her and taking photos of her innovative creations. When was asked her what had inspired this increased innovation, Cindy told us that even many things are simply not designed to be used by people of all abilities, and even the tools designed specifically for people with disabilities, such as prosthetics, are not incredibly useful.

Findings:

Upon researching the variety of treatments for disabilities and talking to Cindy, we began to see the difficulties that arise when able bodied people design products and systems for people with disabilities without including them in the conversation or in the design process.

One specific case that we found during our research for the book was the different approaches to education of members of the deaf community. Early on, schooling in the deaf community happened in sign language, with the signs themselves moving from France and England to America and beyond, evolving along the way. In the early 1900s, a new style of teaching deaf children started, called the oralist method, or oralism. Oralist teaching was exclusively based on learning to speak. Sign language was outlawed in schools, with students being forced to sit on their hands if they tried to sign. Some fingerspelling was used, but for the majority of the time, the teaching and learning all was built around the idea that it was better for deaf people to speak and lip read.

This was an extremely difficult time for the deaf community. Their language was being taken away by people who weren't members of their culture. Even with teaching since birth, deaf children will never speak exactly like hearing people. The oralist teaching was, to the deaf community, an active attack on the existence of their culture. Without a language, of their own, they were forced to try and fit into a world built for hearing people, that often times was simply not suitable for deaf people.

There are still very painful memories in the deaf community from this time, proving how detrimental systems designed by able bodied people to "save" disabled people can be. By actively taking away the agency of an entire community of people to share their experiences with their peers, in their own language, the instigators of oralist teaching did incredible damage. The assumption that the creators of oralism made, that they, as able bodied people, had a better understanding of how do something directly related to a disability better than the community of people with that disability is unfortunately both common and still present.

Most of the time, the designers and inventors of miracle solutions are well intentioned. They see a chance to have a positive impact on someone's life and want to take it. This has led to the creation of many incredible technologies that do really help people with disabilities. The problems arise when the creators get caught up in creating and forget about the actually people that they are creating for.

Take, for example, the MyoElectric prosthetic hand that Cindy has. You'll notice I said "has", not "uses". That is because the almost $90 thousand hand, with 24 different

motions and carbon fiber construction, sits in the back of her closet. Cindy rarely uses the hand, stating that it's too bulky and "looks like a Darth Vader glove". When we met with Cindy to discuss her different tools, she showed us the hand. It was very impressive, with individually actuated fingers and a very futuristic, science fiction look. As Cindy worked to put the hand on, she explained to us the reasons why she doesn't use the advanced prosthesis. The arm is heavy, it's very eye catching, and some of the functionality are unneeded for everyday use. Thousands of hours of engineering went into making this hand, and Cindy spent days setting it up and learning how to use it. Regardless, Cindy do not use it often, certainly much less than the constant use that most engineers would dream of.

After discovering the limits of what the existing tools could do to make her life simpler, Cindy took matters into her own hands. When she found that she could no longer open the container of lotion with a large twist top without help from her husband, she had her husband put a plastic hook with an adhesive back on to the top of the jar, which helped give her the ability to hold the top and open the jar. She got inspired by her creation and started to make more solutions.

Cindy's solutions, which we documented on engineeringathome.org, range from simply adding zip ties to drawers and zippers so she has something to grab, to working directly with a prosthetist to create custom tools. After starting her journey as a designer, Cindy was talking to her prosthetist during an appointment to adjust her prosthetic leg and mentioned how much she missed writing notes and cards. The prosthetist, Grieg, then came up with an idea to fit a plastic cuff

over the remainder of her hand and then sticking a pen in it. He worked with Cindy to create and fit it, and the results were amazing. Cindy lit up when she demonstrated the pen cuff for us, explaining that she even had the same handwriting that she had before the amputation.

While Cindy's solutions aren't highly technical or fancy, they do the exact jobs that she needs them to do. The pen cuff helps her write. The cuff that had a fork in it instead of a pen allows her to feed herself. Her low tech solutions to individual problems have helped her regain the some of the independence that she lost after the accident. They also have the advantage of being designed by someone who perfectly understands Cindy's experience, ensuring that there aren't any unnecessary features or things that don't work.

So what happened? Where did the connection between designer and user fall apart? To put it simply, the creators fell into the common engineering trap of scratching their own itch. When creating a new product, it is very easy to get caught up in designing it in a way that looks impressive or adding features just because you can. As the product become more and more about the engineering, the user centered aspect of the design falls by the wayside. This is what happened with the MyoElectric arm, and it also explains why Cindy doesn't find it useful.

Both of these cases demonstrate the main lesson that we as a research team learned over the course of the summer; in order to truly have a positive impact as a designer, or engineer or creator, you must constantly keep the entire process, from idea to final product,

inclusive. Inclusive, in this case means that members of the community that the project is being created for are included on the team or consulted with as experts. Someone who isn't deaf will never fully understand the full experience of someone who is deaf, just ask an able bodied engineer will never know what it's actually like to use the prosthetic that they have created. By recognizing that the design should always defer to the individuals with firsthand knowledge of a situation, teams and creators can make things that will better serve the people they were built for.

Conclusion:

The research that Professor Hendren's team, myself included, conducted last summer was able to tie smaller projects together into the broader umbrella of inclusive design. While both projects had very different foci and deliverables, both ended up centering on some key ideas. One, that current design structures can be very non inclusive, which can led to negative side-effects, or tools that the target group does not find useful. Two, that in order to make innovation more inclusive, actual people from the communities that are being impacted need to be involved in the entire process. Lastly, by including and recognizing the contributions of people with disabilities, more innovations will be made that will actually have a positive impact on society.