## EXHIBITIONS

## *Human +,* an Exhibition Reflecting the Voices and Lives of People with Disabilities

ERIC SIEGEL

One day in 2002, I brought a designer friend to meet with our daughter, Lili Siegel, to try to figure out a better way for her to walk. Lili has Cerebral Palsy, which is like having a perinatal stroke. Like a stroke, CP affects people in many different ways. In her case, it disrupts the electrical signals between her brain and her legs; she can't walk independently. She mostly uses a crutch around the house, and outside she uses a walker, pretty much like the ones that older stroke victims use, except hers wraps around behind her.

The conversation with the designer was frustrating to me. I also saw that it was a bit baffling to the 10-year-old Lili. Having been raised using a walker, Lili didn't really have a frame of reference for what was possible. Can it be pink? Can it fold itself up when I don't need it? Can it roll by itself when I am in it? Can it be stronger, or weigh less? Can it grow with me as I grow? Can it be personalized? These are all possibilities that a designer can well envision (and a parent too, I might add), but that Lili as a young girl with CP could not articulate.

The conversation didn't result in a new walker design, but it did generate a line of thinking that proved to be fruitful and rich. How can all people—and particularly those with disabilities—participate in designing the things that are important, if not critical, to their lives? How is technology integrated into all of our lives, and how do we, as users, gain more

control over this technology? Is every bit of the technology that we use—Google, glasses (and Google Glass, the wearable computer), shoes, cars, telephones, streets—fundamentally a prosthetic? Is disability a socially constructed issue or a personal issue? Can one accurately say that disability arises only when society does not meet the needs of individuals? Or is there something more specific, deeper, and more intrusive for people who are blind, deaf, or have mobility impairments? What are narratives of disability that can be compellingly and thoughtfully shared with the public to replace the heroic or pity narratives that dominate the public perception of disability?

In 2001, the journalist John Hockenberry wrote a brilliant synthesis of engineering and techno-utopianism in *Wired* magazine. In this article he declared:

We live at a time when the disabled are on the leading edge of a broader societal trend toward the use of assistive technology. With the advent of miniature wireless tech, electronic gadgets have stepped up their invasion of the body, and our concept of what it means and even looks like to be human is wide open to debate. Humanity's specs are back on the drawing board, thanks to some unlikely designers, and the disabled have a serious advantage in this conversation. They've been using technology in collaborative, intimate ways for years—to move, to communicate, to interact with the world.[1]

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**Photo 1.** In the *Human +* exhibition, the "Design a Wheelchair" station. *All photos in this article are by Eric Siegel. View other photos from the exhibition on Flickr at esiegel2.*

## EXHIBITION DEVELOPMENT FOR HUMAN +

As the old adage goes, when all you have is a hammer, every problem looks like a nail. When you work in a science center, every interesting question is a possible exhibition. So we began planning an exhibition in 2009 that we called *Human +*, about how technology is augmenting everyone's abilities, with a focus on people with disabilities. I began the work of looking for part-

ners who shared our interest in the topic, and was fortunate to encounter the Quality of Life Technology Research Center (QOLT), a consortium of engineers at Carnegie Mellon and clinicians and researchers at the University of Pittsburgh. Their focus was what one of the QOLT founders, Rory Cooper, called Participatory Action Design, a cycle of design that deeply integrates the user (Ding et al. 2007).

Cooper, who uses a wheelchair, was using Participatory Action Design to address the

challenges of people who have limited mobility, sight, and hearing. Specifically, he was working with veterans, who are coming back from war with increasingly severe injuries—an unanticipated result of advances in emergency medicine on the battlefield—and the elderly, a rapidly growing portion of the population in the developed world.

We were also fortunate to partner with the Oregon Museum of Science and Industry, where the exhibition team has built deep capacity for evaluation, design, and fabrication of compelling exhibitions of all scales and for all ages. We also were eager to work with OMSI because they have a strong traveling exhibition program that would assure the widest possible dissemination of *Human +*.

As the proposal evolved, we began to look into the significant body of research that suggests that women would be more attracted to engineering if the profession were presented as a more human and social undertaking that addressed human and social problems, as opposed to a geek-fest mashup of applied physics and math (National Academy of Engineering 2008). Participatory Action Design, which puts end users at the center of the engineering process, along with QOLT's focus on addressing human needs through engineering, formed a valuable basis on which to test the alternative strategies to engage girls in engineering.
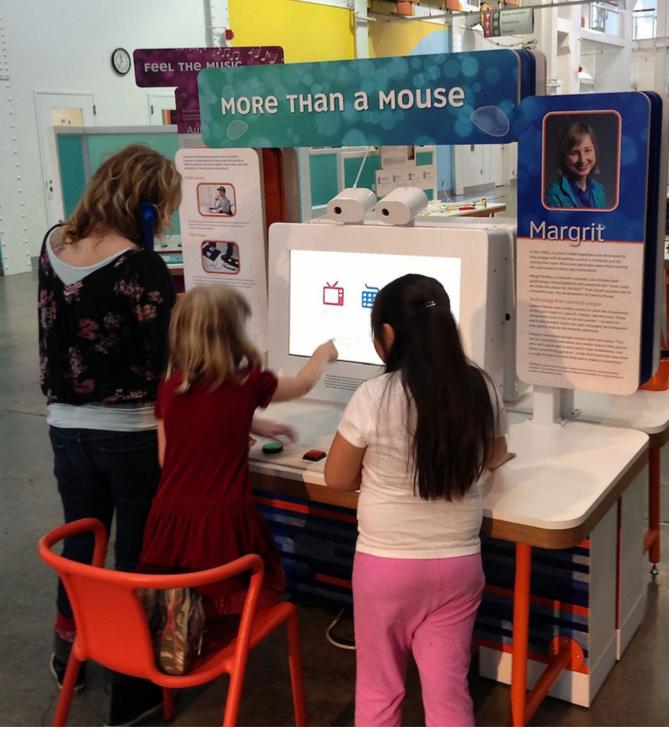
John Hockenberry, who was a research fellow at M.I.T. Media Lab in 2007, provided another valuable inspiration with a conference he produced at M.I.T. to kick off an initiative called Human 2.0.[2] The manifesto for this initiative asserts, with characteristic modesty:

> A science is emerging that combines a new understanding of how humans work to usher in a new generation of machines that mimic or aid human physical and mental capabilities. Some

150 million of us are over the age of 80, while 200 million of us suffer from severe cognitive, emotional, sensory, or physical disabilities. Giving all or even most of this population a quality of life beyond mere survival is both the scientific challenge of the epoch and the basis for a coming revolution over what it means to be human. To unleash this next stage in human development, our bodies will change, our minds will change, and our identities will change. The age of Human 2.0 is here.

Embedded in the dual inspirations of QOLT's Participatory Action Design and Hockenberry's techno-utopianism is a tension that pervaded the development of the exhibition. On the one hand, there are technologies that fulfill quotidian needs that we all have: to work, to play, to communicate. On the other hand, there are aspirational technologies that have their roots in the laboratory and the imaginations of engineers and researchers. *Human +* lands decisively in the former camp, by focusing on how technology is integrated into the daily lives of people with and without disabilities, and placing blue-sky technologies within this context. The exhibition is about human abilities, human activities, supported and augmented by technology, not an exhibition principally about advanced technologies.

## INTEGRATING USERS' VOICES INTO *HUMAN +*

Reflecting the design cycle of Participatory Action Design, *Human +* integrated participation from people with disabilities, both as users and as designers of technology. The original intention was to have a series of residencies during the exhibition's development. However, reduced funding from the National Science Foundation led to one joint group residency and

**Photo 2.** "More than a Mouse" (a computer mouse guided by a person's head movements). Each station identifies its designer; Margrit is shown at right.

ongoing contact through various online facilities. The face-to-face residency was led by Kathy McLean, who has built a strong body of knowledge and experience about co-creating exhibitions and programs. The residents were the core team of exhibition developers from NYSCI and the Oregon Museum of Science and Industry; three young people with mobility

disabilities (including Lili Siegel, my daughter mentioned at the opening of this article, now 21); three participants from QOLT, including two engineers with disabilities; content experts; and evaluators.

The residency began by exploring the narratives that might guide the exhibition. We were determined that the "voice" of the exhibition be created by those for whom the subject of disability is most pressing and present. One of the key insights for this aspect of the work was to avoid either the "heroic" narrative of disability (applied to the likes of Oscar Pistorius, Stephen Hawking, Aimee Mullins, and other superstars with disabilities), or the "pity" narrative, as presented in countless movies, television shows, and so on. There was also a strong "keep it simple" bias about technology, even among the engineers. Low-tech solutions were much more relevant to their lives, rather than the latest advances in neuro-prosthetics.

We also explored carefully and deeply the idea of disability being socially constructed. In other words, did our residents believe that disability only arises when the environment does not meet the needs of the individual? Or is there a sense that people with significant mobility, sight, and/or auditory disabilities expect to have to adapt to the world as it is? While this may seem like an academic distinction, it generated significant discussion, particularly as it applies to the idea of "universal design." Is it true that if all things were designed well, they would be accessible to all? The consensus among *Human + residents* seems to reassert the obvious: that they, as people with disabilities, need specific technologies and accommodations that are not required by people who do not have disabilities.

One resident, Ira Socol, an educator who writes about new universal approaches to learning, led the group on a series of thought experiments, through which we analyzed our own dependence on technology, whether or not we had a disability. To get from NYSCI to Manhattan, he asked, what technologies would we need to use? In addition to subways, Google Maps, and bridges, we all explored the technologies we take for granted: our shoes, our glasses, the roads, the metal in the staircases. When viewed through this lens, we are all fundamentally dependent on technologies in our daily lives, and the reliance upon technology of a person with a disability is only different in degree.

A series of design challenges was undertaken by teams of residents. The first challenge was based on objects or pictures of objects or conditions that were impediments to them in their day-to-day lives. The impediments ranged from kitchens to doorways to pet feeding. The residents divided into groups, each of which included at least one person with a disability, an engineer (who may or may not have a disability), an exhibit developer, and a content expert. These groups worked to design solutions that address the participants' daily needs and honor their physical and emotional needs. One of the groups proposed tools that would allow people with disabilities to identify routes and spaces that would be most accessible for them wherever they were. This led to a discussion of a Foursquare-style app in which people would contribute ratings of different locations. One of the first products of *Human+* is in fact the Accesstogether.com app, developed by John Schimmel, one of the *Human +* residents, based on the Foursquare API. Accesstogether.com is now being beta tested in several sites around the world. When the exhibition travels, the team will use social media to invite people at the venues to contribute to the accesstogether.com database.

Throughout the remaining design challenges, the group continued to push on the

**Photo 3.** "Caring for a Pet" gives visitors custom pieces created by OMSI and challenges them to design ways to feed a pet.

human side of disability, which brought on many deep, rich, and poignant discussions. Probably the most influential and broadest conversation emerged around the identity of people with disabilities. Residents asked each other—if they had the opportunity for "normal" functioning—would they want it? Each individual's abilities are fundamental to their identities; by losing their disability, most of the residents thought, they would be losing an important part of their identity. It is true that all of the residents were born with their disabilities, and the answers might be different for people who became disabled through illness, accident, or war. I have to admit, as the parent of a child with a disability, that I thought I had some under-

standing of how disability shaped a personality. From these discussions, I learned that the interaction of disability and identity, like the interaction of race and identity, is more complex and multifaceted than I had understood.

From these conversations, a subtle consensus emerged. *Human +* had to represent the authentic voices of people with and without disabilities, and had to embrace the complexity and diversity of these voices. Joe Heimlich, the researcher acting as evaluator for the residencies and for the exhibition, made the following points:

The process was tremendously powerful in allowing language to shift and to move the resi-

dents into honest relationships. The first day was highly successful in progressing the group from reticence to honorific (and to the heroic) and into mutual respect and engagement…. The process appeared to be extraordinarily meaningful to the residents. The very real change from strangers to colleagues from the beginning to the end was expressed in many ways by individuals. The continued work of the core team appears to have been strongly influenced by the residency. *Human* + should be a more meaningful exhibition for visitors as a result of this experience.

## HUMAN + EXHIBITION DEVELOPMENT

I led the core development team as principal investigator, with Peggy Monahan, creative director for exhibitions at NYSCI, and Vicki Coates and Karyn Bertschi at OMSI. Our core challenge was how to translate those insights into a functioning traveling exhibition. One of the real challenges, which will be discussed in more detail later, was how to keep the residency participants engaged as the project moved from the abstract to the tangible.

The team distilled exhibition main messages from the residencies and ensuing discussions:

### Exhibition Main Messages

- Engineering is a creative process that can design technologies to help meet human needs and improve people's lives.
- You can design technology that helps people use their abilities to achieve their goals.
- Users should be central to the design process, since they can give engineers important information about the real problems they're trying to solve, and can help make sure the tools will actually work for them.

- The field of assistive/adaptive/prosthetic technology is rich with ethical issues.
- We all use technology to better enable us to do things—sneakers and glasses may be more prevalent than prosthetics and wheelchairs, but they're all tools that help us reach our goals.

These main messages were coupled with an exhibition overview that helped to guide the team in creating exhibition experiences:

- *Human* + is an engineering exhibit about technologies designed to augment people's abilities and the creative, user-centered process that's used to develop these technologies.
- The point of view of *Human* + is that all people's abilities are not equal but are on a continuum. *Human* + will embody the idea that "disabled" is not a hard and fast category, but rather a descriptor that can change in time and place. A blind person may not be disabled in the dark, and a wheelchair user can travel faster than many people on foot. As technology advances, the exhibition posits that the category of disabled will continue to change.
- When leaving the exhibition, visitors should see themselves as personal users of technology to enhance their abilities (from sneakers to eyeglasses to wheelchairs and prosthetics) AND as someone who can take a proactive role in designing something for themselves and others.
- We will involve people with disabilities as the authentic voices of the exhibit. They will guide the exploration of: 1) How technology can augment people's abilities, including their own. 2) What they have accomplished, and what their goals, abilities and barriers are. 3) How they've
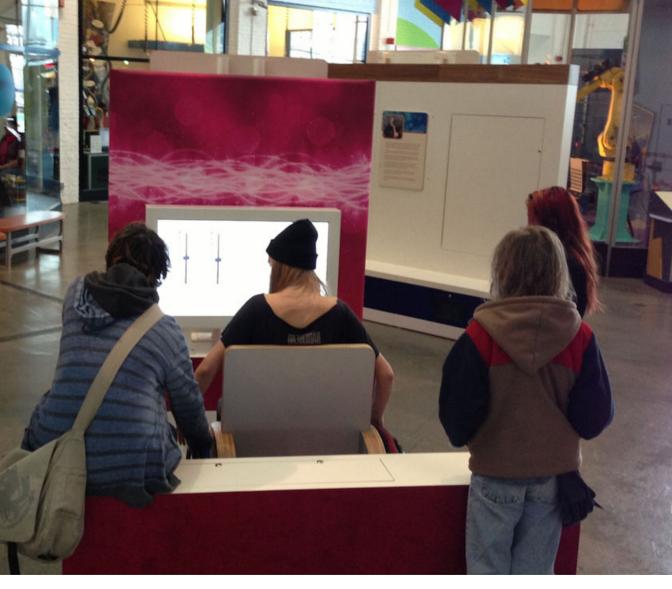
**Photo 4.** Teens use RAMPS to DJ music. A wheelchair transfer board gives access for those who use wheel-chairs.

modified or imagined modifying technology to make it work better for themselves. 4) How they themselves design this technology.

- Other voices can be other engineers that design this technology, and other users.
- There should be some exhibit stations where visitors design and/or build things, but not every exhibit has to be a design challenge.
- The exhibition should innovate at least one new accessible technology and be designed with universal design principles in mind.

While every exhibition development process is different, the development of *Human +* from this stage forward was sufficiently similar to other projects that it does not bear detailed discussion in this article. Formative testing was conducted with a range of audiences, including ethnically diverse girls, people with disabilities, and family audiences.

The focus groups that included people with disabilities and without disabilities were profoundly re-affirming of the input from the residencies: that continual input from people with disabilities is critical to assuring that design

meets real world needs; that the everyday uses of technology are essential to the productive lives of people with disabilities; that engineering to address human needs makes the engineering profession much more attractive to diverse audiences.

The completed exhibition opened for its "test run" at OMSI at the end of March, 2013. It is about 2,500 square feet, designed to travel readily to smaller venues in one truck. The team will be assuring its effectiveness and durability during this six month run. Its official opening will be at the New York Hall of Science in Fall 2013.

## THE *HUMAN +* EXHIBITION

While it is difficult to single out the exhibition components that are most successful until we have conducted summative evaluation, I can give a personal sense of the ones that I feel are most adventurous and thoughtful.

John Schimmel, an artist, designer, and educator affiliated with the Interactive Telecommunications Program (ITP) in New York City, created a wheelchair-driven DJ system for a young man with Cerebral Palsy. Called RAMPS, this design is modified so that visitors to the exhibition can "scratch" digital recordings using a wheelchair.[3] This captures technology responding to a real need that would not be identified without the intimate participation of this young man.

In a similar vein, artist Bill Shannon in Pittsburgh has a degenerative hip condition that requires that he use crutches to bear his weight. Shannon developed a whole vocabulary of dance moves with and without a skateboard, requiring crutches that he customizes. This set of movements is so dramatic and beautiful that he was featured in a VISA advertisement, and the Cirque du Soleil hired him to teach their acrobats.

His video piece, and crutches he made, are in *Attempts*, which shows him and another dancer failing to execute some elaborate moves several times, and finally succeeding.

On a homier note, visitors are challenged to create a mechanism that will allow them to feed their dog or cat. This emerged directly from the needs of Elaine Houston, one of the wheelchair-using engineers from QOLT, who participated as a resident. Houston has a helper dog and lives independently, so taking care of her dog is an ongoing responsibility. The solutions she has developed are very low tech and very reliable, and visitors are encouraged to design their own.

There are a dozen or more stations, so these are just the highlights. Throughout the exhibition, video and text capture the voices of the users and creators of this technology, which helps us to avoid both the "heroic" and the "pitiful" narratives that plague so much work on disability.

## FINAL THOUGHTS AND CHALLENGES

The exhibition was extremely challenging personally. My wife and I have cared for and loved two extraordinary daughters, who, as of this writing, are juniors at Smith College and Amherst College. Lili, who joined with us in creating *Human +*, is working out identity issues related to disability with breathtaking clarity and courage, and we can only marvel how far we have all come in this process. It has been painful to revisit some of these issues. My colleagues and I have been filled with emotion and have gained a deeper understanding of how different abilities can affect people's lives.

As hard as we worked to avoid the "hero" narrative for the residents we collaborated with, we were frankly awed by the courage and integrity they bring to their lives and the deep

thought they have given to how to live a good life themselves, and how to help others live well. My only regret for *Human +* is that we were not able to engage the residents more deeply and in a more sustained way when the exhibition started to go into hard-core development mode.

One of the questions remaining after this process is whether there is a significant difference in perspective between people born with disabilities and people who become disabled later in life. One can readily imagine that a soldier returning from Iraq in his early twenties, newly disabled, has a different set of challenges than a person who has integrated their identity with their abilities from the outset.

I have had the opportunity to see the nearly completed exhibition being used by audiences at OMSI. I was thrilled and moved at the way visitors engaged with the stories of the people who created and used these technologies and how that engagement seemed to encourage their own participation in the exhibition activities. Virtually all of the substantial amount of text is devoted to people first, and then introduces how they rely on different technologies.

The summative evaluation that we have planned for the summer of 2014 will address specifically whether the exhibition has had an impact on people's perceptions of engineering, particularly girls' perceptions. Our front-end studies were very suggestive of the positive impact of the topic on how girls understand engineering, and we hope that we have been able to carry that through into implementation of the exhibition. **END**

**NOTES**

1. Accessed at http://www.wired.com/wired/archive/9.08/assist_pr.html.

2. Accessed at http://h20.media.mit.edu/about.html.

3. The story can be found at http://www.base2john.com/prjcts/index.php/ramps.

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Ding, Dan, Rory A. Cooper, and Jon Pearlman. 2007. *Incorporating Participatory Action Design into Research and Education*. PDF. International Conference on Electrical Engineering, Coimbra, Portugal, Sept. 3-7. Accessed at http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CDcQFjAA&url=http%3A%2F%2Fineer.org%2FEvents%2FICEE2007%2Fpapers%2F553.pdf&ei=5GNtUfveO-zB4APkq4CABw&usg=AFQjCNHSVsvadUvWVAWphAopnH0vK-JpXg&bvm=bv.45175338,d.dmg.

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