
Pimp my Wheelchair!: The Supply and Demand for Personalized Wheelchairs

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Introduction: The Cultural Context of Wheeled Mobility

Returning to my parents' home after completing my sophomore year at UC Davis, the once old-fashioned house that I had grown up in had become sprinkled with new items of assistive technologies everywhere I looked. My parents had recently remodeled the house to make it more accessible for my mother, who has Multiple Sclerosis, a degenerative disability that has caused a gradual decline in her strength over the past twenty years. For the past several years, my family has known that it was just a matter of time before we either moved into a new house or made these changes, but my mother was very reluctant to do either. Over the course of three months, my once hippy-themed house had become decorated with highly conspicuous state-of-the-art technology, changing the overall ambience.

As I adjusted to the changes in the house, I noticed the vast improvements that the assistive technology offered to my mother's quality of life. At first, I mistook the improvements in my mother's mobility with amelioration in her disease. However, as I spent more time in our technological house and observed my mother interacting with this equipment, I realized that she appeared less disabled because the new additions to our house were making up for her body's impairments. Through assistive technology (AT), a term used to encompass all equipment for people with disabilities, my mother had regained many abilities that she had struggled with over the past five years, increasing her independence and accessibility throughout our house and extending throughout the city, by means of her power chairs. Once my mother overcame her original reluctance to use these technologies and welcomed them into our house, the effects of the technologies on her daily life were immeasurable.

Why had my mother been so hesitant to incorporate these technologies into her lifestyle, if they were able to help her in so many significant ways? And were there other people with disabilities out there who could benefit as much or even more than she had? Even though my mother knew that the renovations on our house were inevitable, she put them off until her condition reached the point that the only other option was moving into a flat house. The primary reason for her reluctance, she tells me, was that she knew that once she had the technology, going back to life without it would be more or less impossible.

This dependency on technology made my mother anxious and frustrated that her ability to function like an able bodied person relied so heavily on machines. However, once she had the machines, she ad-

opted new ways of thinking about them that made them seem less mechanical. This was particularly true in relation to her stair glide. Whenever someone visited the house, she insisted that they ride her “roller coaster.” Through renaming her machine, she made it seem less technical and more fun. My mother’s change also changed the way that others thought about the machine; it now received praise, much like that bestowed on a new car or high-tech television set. Because of the amazing help provided by assistive technology, I began to question why this particular type of innovation is routinely viewed and treated differently from other technological marvels and whether this difference was part of my mother’s reluctance to adopt AT.

Returning to school the following fall, I began a new job as a personal attendant for a UC Davis freshman named Alexis who uses a wheelchair. Growing up in a family of lawyers, Alexis was repeatedly taught that she should never accept subordinate treatment because of her disability, and the effects of her upbringing could be seen in her confident and sassy personality. While walking down the street with Alexis one morning, a stranger came up to us and complimented Alexis on an anti-Bush bumper sticker that she had attached to the back of her wheelchair. Although I had noticed her variety of stickers, some political and some humorous, I had not questioned what it meant to decorate her machine. I remembered the way my mother had come to terms with her stair glide, and so I hypothesized that this was Alexis’s way of personalizing her machinery. When considering the American need to convey meaning through virtually everything we attach on our bodies, from our clothing to our Ipods, I began to see the sense in a hip 19-year-old female’s personalization of her wheelchair.

In our rapidly developing technological world, people with disabilities can now increase their mobility by use of an array of products offered by the rapidly expanding assistive technology industry, which leaders of the disability civil rights movement predict will be “the great equalizer of the 21st century.”¹ People with disabilities can either move into an accessible surrounding or take an inaccessible environment and apply technology to their bodies to function more or less “normally.” While the adoption of technology seems the easier choice because it allows people with disabilities to maintain a lifestyle in conjunction with social norms, this decision is more complex.

The decision by people with disabilities to allow AT into their homes does not necessarily mean that these devices get used. Assistive technology scholars have come to realize that the industry’s success in selling its products does not mean that those products are being put to functional use, a trend they call “technological abandonment.”² While American culture rapidly becomes more materialistic, increasing America’s dependency on technology, many people with disabilities are reluctant to use disability technology, resulting in a rate of non-use ranging from 20% to 50% of the technology received by people with disabilities.³ This dilemma, I argue, comes from the complex experience of actually using assistive technology in one’s daily life. When people with disabilities use assistive technologies, they increase their ability to function as normal bodies, but in doing so, they must physically merge their bodies with the technology/machinery, thus simultaneously marking their disability.

I am interested in how people with disabilities adjust to the machinery/technology that becomes part of their functioning bodies, whether or not the enhanced abilities of the machinery forces them to realize the limits of their own bodies, and how they confront outsiders who see them as machine/human. Because wheelchairs are one of the most visible types of assistive technology, I will limit my current discussion to this population. I also question whether the assistive technology manufacturers understand the consumers’ anxiety over the body/machine interface, and what they need to know in order to minimize technological abandonment. In the end, I hope that, between the consumers’ and manufacturers’ attitudes toward assistive technology, I can understand what causes the high prevalence of technological abandonment in the United States.

Although I have seen firsthand the amazing benefits that technology can offer to people with dis-

abilities, I want to make it very clear that I am not suggesting that the technology “cures” the disability. As the work done in Disability Studies illustrates, the concept of disability is socially constructed, so even if technology helps minimize the effects of certain impairments, people with disabilities will still face discrimination. Technology can help, but it cannot be seen as a panacea. Technology offers a starting place for mobilizing people with disabilities, but there is much more to do if we are to succeed in fully integrating those with disabilities into our society.

Buying Mobility: An Ethnographic Study of the Abilities Expos

When I first began discussing my interest with members of the disabled community, I was repeatedly told that if I wanted to learn about assistive technology, I had to attend an Abilities Expo, a traveling show that occurs every two to three months in various cities throughout the United States.⁴ In June 2004, my mother and I decided to take a road trip down to southern California to see whether this convention was as impressive as rumors made it out to be.⁵ In November of that same year, I attended my second Abilities Expo in Santa Clara, California.⁶ Alexis and her mother were shopping for a new wheelchair for Alexis and invited me to tag along so I could see firsthand the complexities of this process.

Throughout my observations as a participant-observer, I found that even though a diverse wheelchair market now exists in the U.S., offering an array of new choices, the access to the technology is restricted by able-bodied retailers whose agenda does not always correspond with that of consumers. On the other hand, the Expos do provide a positive space for being able to appreciate wheelchair technology, much as car buffs appreciate automotive technology at a car show. Therefore, I will argue that the Expos offer a venue with potential: while they allow people with disabilities to act as consumers and create a community where the wheelchair can be appreciated, the inability of the overwhelming majority of able-bodied sellers to think like people with disabilities counteracts the Abilities Expos' success.⁷

BUYING A NEW BODY

When an able-bodied person goes into a store to buy a new pair of shoes, the shoes' design may have some impact on the ability to walk, as any person who has worn high heels knows, but will rarely have a drastic impact on how the shoe shopper moves her body. According to my interviews, on the other hand, purchasing a wheelchair can often feel like buying a new body type. Switching wheelchairs can increase or decrease your height, change your weight, determine your speed, affect how easily you turn around, or just generally alter the way you move. For people using wheelchairs, the technology determines how their bodies perform. Because I am both a personal assistant and friend of Alexis, she and her mother Melinda invited me to join them at the Abilities Expo. Alexis needed a new wheelchair because she was about to have a serious surgery that changed her mobility needs while she recovered. The Expo was Alexis's only opportunity to decide what features she wanted her next wheelchair to offer.

To begin, Alexis and her mother chose the Pride Mobility booth, one of the fifteen sellers of wheelchairs present in the large hall. A youthful, able-bodied male quickly came over, eager to make a sale. The seller enthusiastically showed Alexis two choices of wheelchair models. When Alexis tried out the first of these, she seemed very skeptical of it and could not use it with the ease and comfort of her older chair. With great caution, she moved the chair into the aisle and circled around the booth. She explained to me how strange it felt to try this chair because it made her take up more physical space, something that would definitely require an adjustment on her part. The seller then encouraged Alexis to try the elevating feature, causing the wheelchair seat to raise several inches, allowing her to reach things at higher levels. Because this feature was relatively new to her, she tried this with a look of concern on her face as she gradually climbed in height. Even though this wheelchair satisfied all of Alexis's needs, she was quick to ask me to lift her back into her own wheelchair and appeared somewhat relieved to be reunited with it.

When we moved onto another booth and Alexis tested a Permobil wheelchair, I questioned why she looked so uncomfortable, as she seemed to be leaning forward. She explained that because the seat of this chair is meant for someone larger than she, it was pushing her into this strange shape. The technology was hindering her body's natural position. Alexis's experience shows that if the wheelchair is not the perfect match for its user, the machine itself can be disabling. For a wheelchair to drastically increase the mobility of its user, it must be the perfect wheelchair, as defined by the wheelchair user's unique needs. Choosing the right chair is important in order to ensure that the machine does not control the body but rather the body controls the machine, and that the user can grow comfortable in its operation within a reasonable period of time.

Within a short time, a strange look of frustration came over Alexis and she drew my attention to her old wheelchair, which was sitting empty in the aisle next to the new wheelchairs on display. Without noticing her reaction, another able-bodied, male seller, who was explaining a product to a family, had his hand on Alexis's seat and was placing all his weight against her chair. Alexis looked as if this man were personally violating her, and she asked whether I would tell him to stop. As we walked away, she explained to me that he probably was not hurting the chair, but it is worn in to work for her body, and he could have altered this fit. To Alexis, this wheelchair feels like a part of her, so quite understandably, she feels violated when a strange man touches it. This moment shows that the wheelchair is not just a machine, but rather a part of her body, which makes her task at the Expo such a challenge since she is, in essence, shopping for a new body.

Buying a wheelchair, like buying a new artificial limb or having plastic surgery, is the closest thing available on the market to buying a new body. Alexis's anxiety at the Expo reflects the strange feeling that comes from having the unique task of purchasing a product that changes how her body functions. The wheelchairs offer amazing features, as Melinda, Alexis, and I all observed firsthand, but these features cannot be appreciated fully until the user is able to acclimate to the technology and learn to accept the new ways in which her body performs. Alexis had taken the first step along this path, but much more work would have to be done before she could relate to her new wheelchair with the closeness she has had with her current chair.

Alexis's experience suggests that, despite the challenges, the positive atmosphere of wheelchair pride generated by the Expo attendees helps put a positive spin on things. Many people paraded through the Expo bringing attention to their shiny new wheelchairs. For example, I saw one couple in a loveseat wheelchair just making laps to show off the design. Another man modeled a power scooter by putting on his oversized flashing headlights and circling the convention hall, joking, "I'm a flasher! I'm a flasher!" Furthermore, the back of the Anaheim Expo had a large region fenced off, where people in specially designed sports wheelchairs played an adapted game of football. Whereas in the public realm, the able-bodied tend to stigmatize the wheelchair, the Abilities Expos create an environment in which people can take pride in these technologies, celebrating the increased variety and functions of current models. The Expos become a wheelchair fashion show, where the body and machine are appreciated. Ideally, the technological appreciation shown toward wheelchairs will carry over into the wider disabled community.

While the Expo offers an empowering atmosphere for some, others with disabilities still have limited control over their own consumption, as they take a subordinate role to the able-bodied sellers and attendees. While wheelchairs can have a tremendous impact on the users' mobility, the users themselves must take the primary role throughout the whole process of buying a wheelchair in order to avoid a feeling of detachment from the machine and to ensure that they get the wheelchair that fits just right.⁸ However, at both the Expos I attended, I witnessed people with disabilities whose autonomy was limited because their able-bodied family, friends, and attendants, reflecting the hierarchies of the wider culture, took a dominant position with the able-bodied sellers.⁹ In these circumstances, it is easy to understand

how technological abandonment still occurs, even with those who attend an Abilities Expo. Accepting the body-machine merger is hard enough already, but becomes much more difficult if the wheelchair is selected by anyone other than its intended user.

One family in particular exemplified this. At the Anaheim Expo I watched as a young, able-bodied couple, who was accompanying the woman's elderly mother in their search for a new wheelchair, began talking with a seller. I cannot claim to know the whole story of this family, but it was very apparent that the daughter had taken charge of the interaction with the seller, as they both talked about the mother as if she were not present. While the daughter explained their needs to the seller, her mother would periodically try to chime in, but was generally ignored or only briefly acknowledged. Once the seller had learned of the able-bodied couple's specific wheelchair needs, he made two design suggestions. The daughter quickly insisted that her mother try these out, but the mother was less eager. The suggested design was a large, high-tech wheelchair which included a feature that elevated the seat. The current chair, on the other hand, was simple and small but easy to handle.

Before the mother even consented to trying out the chair, her daughter had lifted her up into the high-tech chair, despite her mother's look of apprehension. The seller immediately took control of the joystick and started moving the wheelchair forward and back, making the mother's anxious look grow even more noticeable. When the seller then began to use the elevating feature, the mother's facial expression turned from fear to frustration. By the time the seller finally gave her a chance to test out the controls for herself, she turned the power off and said, "Do they come any smaller?" The seller quickly dismissed this request and switched his attention to his second design suggestion, which was equally large and high-tech. No longer inconspicuous, I moved on, wondering whether the woman would actually use one of those chairs if her family did decide to buy it. I doubt that these able-bodied family members meant any harm, but they did not seem to understand the complexities of what it means to the disabled user to buy a new wheelchair.

As I walked towards another booth, I watched another man in a wheelchair chatting with a seller about what he needed out of a new wheelchair. The seller quickly began preaching about his company's most state-of-the-art product. The consumer stopped the seller from his marketing speech and asked for something simpler. The seller again returned to his original sales pitch of the more expensive, high-tech chair. If the able bodied do not allow the wheelchair user total control over his wheelchair, then the process of acclimating to the machine will be that much harder. While the support of family, friends, and personal assistants is important in the process of accepting assistive technology, they cannot fully understand the complex psychological processes involved in "buying a new body," and thus they can inadvertently make the process of the user's adaptation that much harder.

That all of the booths representing the major wheelchair manufacturers were staffed entirely by able-bodied sellers, whose economic interests may outweigh their interest in empowering the disabled community, is certainly part of the problem. This was particularly obvious at the Johnson & Johnson's Independence Technology booth, where the Expo's most innovative product, the iBOT, was being showcased.¹⁰ The iBOT's new design, which includes a stair-climbing feature, has the potential to break down a monumental barrier faced by people with disabilities. The iBOT also has a gyroscope installed so that it can balance on two wheels at an elevated height. However, it is a bulky, highly complicated machine. At the Anaheim and Santa Clara Expos, Independence Technology had one of the largest booths, with several demonstrators showing off the iBOTs while talking to interested clients. Almost every five minutes one of the demonstrators would climb a display staircase, demonstrating the iBOTs' revolutionary function, while onlookers watched with dropped jaws.

As I stood and talked to several of the iBOT demonstrators, I quickly discovered that none of them was actually disabled. In addition, these demonstrators saw the machine with such pride that they

seemed not to understand why anyone might *not* want to use it, and showed no awareness of the anxiety that causes technological abandonment. For example, one sales representative that I spoke with said that he doubted anyone would be reluctant to use the iBOT because it has such amazing functions.¹¹ My research, on the other hand, did not find such ease of mind. Most people with disabilities whom I interviewed said that they did not think they could ever use a machine like that because trusting it with such a precarious task as stair climbing would be too scary. When I interviewed Alexis about this product and the display at the Expo, she was highly skeptical of the iBOT, stating, “If I fell as opposed to them [the able-bodied sellers] it is going to be a lot worse for me. I just don’t think they realize how much one has to physically rely on the technology and it’s scary to rely on technology like that....It scared me.”¹²

Alexis’s strong apprehension suggests that the iBOT sellers may have overestimated the real demand for such a high-tech machine. It is possible and perhaps even likely that, even if the iBOT demonstrators had been disabled, the clientele still would have been wary of the iBOT. However, the lack of any disabled demonstrators made Expo attendees such as Alexis even more suspicious of this product, making it even less likely that this product will achieve widespread usage. The iBOT technology has tremendous potential, but marketing it entirely by able-bodied sellers has the effect of isolating the disabled from this technology even before they have a chance to try it out for themselves.

My discussion with the iBOT sellers exposes an even bigger problem associated with having able-bodied sellers. The able-bodied seem to be thinking about the process of buying wheelchairs as if it is no different from buying a new car. It makes me wonder whether able-bodied people will ever really be able to understand what the wheelchair means to people with disabilities. As an able-bodied person myself, I like to believe it is possible, but I am not so sure, because as Alexis emphasizes, the able-bodied iBOT seller will always be able to jump out of the wheelchair if it malfunctions.

Thus, while the Abilities Expo offers an environment where people with disabilities can marvel at the new technology and be free of the stigma they encounter in their everyday lives, more can be done in order to help foster pride in and ownership of the new technology. If all sellers and demonstrators are able-bodied, it will counteract the benefits the Expo brings by re-introducing the hierarchy of the wider culture, where the able-bodied profit off of the disabilities of others. To increase the choices available so that it is easier to get a wheelchair with a Cinderella-shoe fit, people with disabilities must play a greater role in the whole industry, including both production and consumption. The technology has the ability to offer great mobility, but just providing a wheelchair is not enough.

Dehumanized Bodies, Personalized Machines: Learning to Accept Wheelchairs

As a philosopher and sociologist of science with the privileged opportunity of interviewing Stephen Hawking, Helen Mialet set out to examine where the machine ends and the body begins for a man of such amazing mental capacities who simultaneously must rely heavily on machines.¹³ In her essay, “Reading Hawking’s Presence: An Interview with a Self-Effacing Man,” Mialet describes the relationship between his body and his many life-preserving machines.¹⁴ What most interested me about her essay was a specific moment in the interview that she mentions without explanation. In the middle of one response, Hawking has to pause because his current wheelchair battery needs to be replaced with a fully charged one. Mialet illustrates this moment, stating, “She [the nurse]...begins to manipulate a big black box under [Hawking’s wheelchair] marked *Mozart*....Tom [another assistant]...inspects something under Hawking’s chair. He leaves the room and comes back quickly with a big black box with *Mahler* written on it.”¹⁵ Although I cannot be certain who wrote “Mozart” and “Mahler” on these batteries, I could not help but wonder whether Stephen Hawking, one of the most well-known and highly respected wheelchair users to date, did so himself in an attempt to personalize his chair, much like Alexis had by displaying political bumper stickers on her wheelchair.

The trend can even be seen in popular culture. While browsing on Ebay one day I discovered that Mattel sells a Barbie doll (named “Becky”), who rides a wheelchair with wheels that sport a flashy hologram insert. If this trend extends from a Barbie doll to a scientific and mathematical genius, with everyday people like Alexis in between, then I wanted to know whether there was a deeper meaning behind the act of personalizing one’s wheelchair. Unable to ask either Becky or Hawking, I set out to find members of the disabled community who had personalized their wheelchairs.

The fact that, as I witnessed at the Expos, people with disabilities are often excluded from the process of selecting their wheelchairs renders the technology meaningless to its user except as an object of stigma. Decorating wheelchairs, however, offers wheelchair users a chance to claim the wheelchair as their own. By conducting four interviews with people using highly personalized wheelchairs, I came to understand the many benefits, beyond mere aesthetics, of decorating wheelchairs. Since all of the interviewees were able to walk at one point in their lives, they shared stories of the difficulty adjusting to a wheelchair, and in particular, being seen and often stared at in public.

GIVING THEM SOMETHING TO STARE AT

I hope to make it clear that, although my focus is on people with disabilities, the cultural factors leading wheelchair users to want more than utility from the technology affects the able bodied as well. A look at the history of the automobile makes this more apparent. The first automobiles on the market were so costly that the technology was initially seen solely as a product for the bourgeoisie.¹⁶ Henry Ford changed this, however, by bringing out the Model T, pursuing his dream of a “motorcar for the masses.”¹⁷ In *Auto Opium: A Social History of American Automobile Design*, sociologist David Gartman looks at the way the working class felt towards this technology and its aesthetics. Even though Ford’s Model T allowed the working class to purchase automobiles that they otherwise could not have afforded, and thus imitate the bourgeoisie, they were not entirely satisfied. Gartman elaborates:

The ugliness of the mass-produced products they bought to fill their refuges from the Fordist factory did not allow workers to totally forget the oppressive workplace. When compared to the ‘classy’ consumer goods of their employers, products like the Model T were immediate reminders in consumption of the class gap between labor and capital in production.¹⁸

By the time Ford realized this, it was too late, as General Motors had stepped in to offer a wider variety of choices to the working class.¹⁹ Alfred Sloan, the president of GM at the time, recognized that they could not beat Ford in a price war, so he instead decided to focus on style.²⁰ GM began mass-producing cars with an art deco style, offering the masses the appearance of luxury for a price close to that of Ford’s Model T.²¹

Although the Model T allowed the working class the mobility of the upper class, its look simultaneously marked their subordinate status. Similarly, wheelchairs allow people with disabilities increased mobility, but because the machine marks their “otherness,” many people with disabilities want wheelchairs that reflect their personal identity as well. Just as some users of the Model T wanted the machine to represent something other than their working-class-ness, so many wheelchair users want their chairs to show something more than their disabled-ness. What General Motors’ success over the Model T shows us is that Americans are not necessarily rational about their machines. Utility does not always come first. Rather, we want style and character, even if it means paying slightly more for it.

In the case of wheelchairs, the demand is even more significant because they are used all day long. The interviews I conducted with four wheelchair users showed that they decorate wheelchairs for reasons similar to those that drove people away from the Model T and toward GM cars. A 50-year-old woman

named Ruthee, who has Multiple Sclerosis, rides in a wheelchair on one of whose footplates sits a doll of Margaret, the cartoon character from *Dennis the Menace*, which she has covered with political buttons. She explained that, reading the newspaper one day, she had come across an article arguing that Margaret offers a feminist role model for girls, unlike the more popular Barbie doll.²² In the cartoon, Margaret is always quick to challenge Dennis the Menace, disregarding gender norms. In addition, Margaret frequently yells to Dennis, “Someday a woman will be president!” Ruthee, a feminist activist herself, greatly identified with Margaret and ordered a doll immediately after reading the article. Then she began to attach political buttons to Margaret to show others her many ardent opinions. These wheelchair decorations most assuredly serve a personal purpose beyond aesthetics. For Ruthee, Margaret shows the public something about her personality, forcing people to look past her disability and see the complexity of ways in which she is unique.

Although it is unlikely that a stranger will look at Ruthee’s doll and understand the feminist symbol she represents to Ruthee, her wheelchair decorations serve a secondary purpose as well. She feels they help make the able-bodied public feel more comfortable around her wheelchair. Because passers-by ordinarily either stare at wheelchair users or look away as if they do not exist, the interviewees add decorations that invite people to stare while simultaneously controlling what they are staring at. Ruthee explained, “It’s a comfort zone for others emotionally because it makes you more real, I guess, and normal, and less of a machine-thing.” By using her doll to open the lines of communication, Ruthee encourages people to get to know her, rather than being unable to see beyond her wheelchair and disability. This is especially significant because her doll appeals to children, offering Ruthee the chance to shape their perceptions before being fully socialized into the cultural stereotypes about disability. Because stereotypes about people with disabilities create such widespread misunderstanding, Ruthee’s doll helps create a bridge for the able bodied to move across as they get to know Ruthee and begin to overcome their misconceptions of the disabled community.

Charles, a paraplegic, has similarly designed his wheelchair to help change the way the public responds to him. Ten years ago, Charles decided to make his wheelchair a bit flashier and designed inserts that fit into his wheels. When I asked him why he did this, he answered, “I just wanted to go do this, dress it up a little bit and not be just another regular plain looking chair....It personalizes it. To me, it tells me who I am, how I like things.” Charles expressed the same core reason as Ruthee had for decorating his chair: he did not want to be reduced to a wheelchair by the viewing public, so he invented these spoke guards to distinguish himself.

As I had begun my research in part because of Alexis’s wheelchair, I interviewed her as well. She began decorating her wheelchair six years ago by putting a single bumper sticker on the back that soon turned into a whole collection of them. Her current stickers cover the gamut of topics. For example, her three largest ones say, “Freedom to Marry,” “I’m Not in the Mood to be Stared At!” and “Chicks Rule!” But not all of her stickers are so political, such as a blue and gold one that reads, “UC Davis Aggies.” Although she originally started doing this just for fun, it later served a dual purpose, as a means for visibly conveying her identity to others through her chair. Alexis articulated this, stating, “It’s my way of being able to make a statement to people....People see me and they see a girl in a wheelchair, but if they also see some profound political statements on the back, then they go, ‘Oh wow, she actually has a personality and feelings about certain issues.’” Having gone on many outings with Alexis, I can vouch that her stickers do exactly this. On several occasions, we have had strangers come up to us and compliment Alexis on her choice of stickers, agreeing with her political views. By using the space of her chair to express aspects of her identity outside of her disability, she refuses to be reduced to just another person in a wheelchair, and all of the stereotypes that come with it.

Erin Schey, my fourth interviewee, has had Cerebral Palsy her entire life but has used a wheelchair

for only the past five years, after a failed surgery. Erin acquired a large collection of stickers on her wheelchair, but unlike Alexis, her stickers tend to focus less on politics and more on religion, such as stickers that say, “Girl for God” and “I Have Issues.” Like the other interviewees, she explained that the significance of decorating goes beyond aesthetics: “People in my community...weren’t very open to me...but I found once I started putting the stickers on my chair, I found people commenting...and it would start conversation...I think it’s a way to take a general piece of equipment, which a lot of disabled people have and make it your own.” Like the other interviewees, Erin found that decorating her wheelchair made it easier to both fit in and stand out at the same time.

The decision to decorate rests on the assumption that the able bodied will stare at people using wheelchairs, providing an audience for their wheelchair decorations. As disability scholar Rosemarie Garland-Thomson argues in her essay, “Seeing the Disabled: Visual Rhetorics of Disability in Popular Culture,” “As anyone with a visible disability knows, being looked at is one of the universal social experiences of being disabled....It manifests the power relations between the subject positions of ‘disabled’ and able-bodied.”²³ Similarly, when my interviewees discussed the significance of their decorations, they spoke about able-bodied voyeurism as if it were an inevitable aspect of living in a disabled body. However, the interviewees felt that their decorations also encouraged people to stare, thereby allowing them to gain control over the stare by making it happen on their own terms. In this way, the interviewees were able to overcome the discomfort of this once unwanted attention. While all of the interviewees expressed this sentiment, Erin most clearly articulated it, claiming that her decorated wheelchair “makes it more comfortable to have people look at me because maybe they’re not staring at me but they’re looking at my stickers....Make them really look at the chair and not just that we are in a chair because you know it will really shift the people’s focus.” By using the attention for their own purposes, the interviewees are transforming the meaning behind able-bodied staring. No longer an oppressive and hurtful act, it has come to be a welcomed and educational opportunity.

Although the decorations all send different messages, their effects on the able bodied are similar. The able-bodied people become an audience whom the wheelchair user can then educate, showing what it really means to be disabled. Rather than being seen as malicious, the able-bodied stare becomes an attempt to learn what it means to use a wheelchair and have such a close relationship with a machine, something the able bodied know little about. Wheelchair personalization turns voyeurism into a dialogue between those who stare and the stared-at. In a perfect world, people would not stare in the first place, but since we still have a long way to go, a powerful short term strategy allows the stare to occur, but does so in a way that empowers those who are stared at rather than objectifying them.

This is particularly noticeable with my favorite sticker on Alexis’s wheelchair, which says, “I’m not in the mood to be stared at!” This glittery sticker attracts even more attention than she would ordinarily receive, but then criticizes the voyeurs, rebuking them for staring in the first place. This sticker shows that she is comfortable with her disability and does not feel she deserves attention, teaching people not to stare, which many may not even realize they do. By helping the four interviewees better identify with the technology and by showing the able-bodied voyeurs that people with disabilities are much more than their wheelchairs, the act of decorating wheelchairs serves a complex cultural purpose that cannot be reduced to simple aesthetics.

Everything said thus far about personalizing wheelchairs—that it helps users identify with their machines, that it offers a means of opening communication with the able bodied, and that it can be used to invert the meaning of the able-bodied stare—derives from a more all-encompassing need that the interviewees addressed: the need to accept the wheelchair and come to terms with it as a newfound part of their identity and daily life.

Each of the interviewees explained that it was not until they stopped denying their disability and be-

gan accepting the wheelchair for its benefits that they were able to even consider decorating their wheelchairs. For example, Erin believes that many people with disabilities do not feel comfortable enough to personalize their wheelchairs because they have not accepted their disability, arguing, “a lot of people just don’t accept the tool ... and they know that once they do use it, people will treat them differently.... It’s a sign of acceptance. When you personalize something you are accepting it for what it is.” As seen in Erin’s statement, personalizing the wheelchair is a step in the process of accepting it and thus accepting the reality of the disability. The comments of interviewees suggest that in personalizing wheelchairs, acceptance becomes that much easier because the decorations make it more personal.

A STEP PAST ACCEPTANCE

The process of acclimating to wheelchairs does not end with acceptance of the tool, however. Personalizing wheelchairs offers a way for people with disabilities to determine for themselves the meaning of the technology, avoiding the stigmatization of disabling stereotypes of disability. With personalization, however, comes a new complication, a feeling created by not being able to distinguish whether or not the technology is part of their bodies. When asked whether they see the wheelchair as part of their bodies, the interviewees all said that once they decorated the wheelchair and accepted it as part of their identity, they began to see it as less of a machine and more of an extension of their body. They acknowledged that, because it functions as an extension of their body, it cannot be considered separate. On the other hand, the interviewees each compared their wheelchairs to how able-bodied people use everyday technologies, specifically referencing automobiles. As I re-examined each of the interviews, I realized that the comparisons with mainstream technologies serve the purpose of helping wheelchair users grapple with the extra complex body-machine overlap.

Just taking a walk down any city street counting the number of people using cell phones or iPods shows how popular it has become for us Americans to adorn our bodies with technology. The difference for those with disabilities, however, is that they cannot detach themselves from their wheelchairs in the way that the able bodied can from their devices. Because the interviewees depend upon the wheelchair for their mobility, they consider it part of their body. At the same time, they rationalize their dependency by drawing a parallel to the wider culture’s attachment to technology.

This paradox was highlighted earlier, in the scene where I described how violated Alexis felt at the Expo when a stranger was touching her chair without permission. At the same Expo, I sat in on a seminar focusing on methods for coping with disabilities.²⁴ One woman raised her hand and shared a recent frustrating experience. While riding an elevator, she realized that a stranger was leaning against her wheelchair. The woman in the wheelchair turned back to the stranger and complained. When the able-bodied woman said she did not understand what she had done wrong, the disabled woman reached up and grabbed the stranger’s ear and said, “When you touch my wheelchair, it feels kind of like this.” Implicitly differentiating between the wheelchair and other mainstream technologies, the woman had equated the wheelchair with an earlobe, clearly showing her belief that her wheelchair is a part of her body.

The people I interviewed offered similar encounters, all indicating that they see their wheelchairs as part of their bodies. For example, Ruthee recalled, “People don’t get that when they kick our chair, move our chair while we’re in it, or touch our chair without necessarily touching our body, there’s no difference....The chair is part of me!...People don’t understand that this is not a place to sit, it is not a piece of furniture, it is who we are, it is an extension of ourselves.” As Ruthee’s quote illustrates, some people with disabilities come to see the wheelchair as not only a tool of mobility, but rather as “who we are,” blurring the lines between the body and the machine. Given this highly personal relationship with the wheelchair, it makes perfect sense for wheelchair users to decorate the machines, visually marking the relationship between the body and the wheelchair. No one thinks twice about wearing clothing and

jewelry that show off our individual sense of style, so why not do the same with a wheelchair, since, as Charles said, “It is our legs”?

Personalizing wheelchairs allows users heightened control over their bodies and the cultural meanings attached to them, helping the users become more comfortable with both their wheelchair and their disability. Yet this behavior has yet to be acknowledged by rehabilitation therapists, who are trying to find out why people are unsatisfied with whatever chair they are given. What seems to be missed here is culture. Wheelchair users must mediate between the stigma of disability and the wider cultural values towards technology, a conflict that is played out on their wheelchairs.

This highly intimate relationship with a machine is not limited to people with disabilities, however, as can be seen in the MTV reality show, *Pimp my Ride*. In the show, hosted by rap musician Xzibit, a group of automobile mechanics helps spruce up people’s extremely dilapidated cars, turning them into cars that are highly personalized. For example, one person who was selected to have his Volkswagen van “pimped” was very committed to surfing, and so the *Pimp My Ride* team made his car fully equipped for trips to the beach, as well as decorating the interior to meet his surfing lifestyle.²⁵ In this show the desire to want style out of cars seems perfectly rational. Yet when wheelchair manufacturers design wheelchairs, style usually gets left out. If it’s natural for us to decorate old, dying cars—and I should add that *Pimp my Ride* never touches the engines, a fact indicating that the show’s appeal is based on the power derived from aesthetics rather than from technology—does it seem strange that the disabled should decorate their wheelchairs? Why shouldn’t they be able to have someone “pimp their wheelchairs”?

“We work with them”²⁶

When the disabled voice is marginalized or excluded altogether from the design, production, and marketing of wheelchairs, as I witnessed at the Expo, decorating wheelchairs offers a means for growing more comfortable with the technology. Although it is clear that decorating their wheelchairs has benefits for both the users I interviewed and those among the able-bodied who interact with them, I wondered if there was more that could be done to ease the process of using wheelchairs. Upon first hearing about Whirlwind Wheelchair International (WWI) from another disability studies scholar, I knew I had found an answer. WWI, a non-profit group of wheelchair designers and builders, incorporates wheelchair users into the whole process of production. This inclusion helps them create wheelchairs that have been designed and built solely for the intended user and often constructed by them as well. The result is that users easily acclimate to their machines. Ralf Hotchkiss, founder of WWI, explained very simply what WWI does for people with disabilities that the U. S. manufacturers miss, saying, “We work with them.” By doing so, WWI manages to include the wheelchair users’ identities into the design process, rather than leaving it to the users to decorate the wheelchairs themselves.

THE HISTORY OF WHIRLWIND WHEELCHAIR INTERNATIONAL

Ralf Hotchkiss has been a “wheelchair rider,” the term he prefers, since he was in a motorcycle accident in 1966. He quickly got interested in wheelchair manufacturing when he received his first wheelchair and discovered “the grim reality of the wheelchair consumer: the selection was limited; the quality was poor; and the machines were designed for the convenience of the manufacturer, not the consumer.”²⁷ His wheelchair was so large that he could not even enter the doorway at his workplace. Frustrated at the lack of customization available for wheelchairs, he became an expert in altering them, and soon began tailoring wheelchairs to fulfill the neglected needs of the riders.²⁸

In 1980, Hotchkiss traveled to a small rehabilitation center in Managua, Nicaragua, where he got the idea to establish a wheelchair shop, Nicaragua’s first, which trained local people with disabilities and ensured that their specific wheelchair needs were being addressed throughout the design and production

process. The success of the shop motivated Hotchkiss to expand his efforts to other Third World countries. Only one percent of the twenty million people in Third World countries who need a wheelchair owns one.²⁹ Those who do not have access to a wheelchair either spend most of their time in bed or use untraditional means for getting around. For example, Hotchkiss met one teenager in Mexico who had his brother drag him on a board in order to attend a Whirlwind workshop.³⁰ Although Americans with disabilities are far from satisfied with the U.S. wheelchair industry, they have a great advantage over people in less developed countries who do not even have a wheelchair, let alone a personalized one. Hotchkiss created the Whirlwind Wheelchair International Project, a group of engineers who head out to different Third World locations and teach locals to set up a shop that can design wheelchairs that are ideally suited to the region—designs, that is, that both fit the local culture and use local materials to keep costs as low as possible. Before they begin designing wheelchairs for a specific region, they speak with the local disabled community and observe the local culture, providing them with a keen understanding of the cultural context in which the wheelchairs will be used and designing them accordingly. Although some members of the group are able-bodied, WWI is committed to having a majority of people with disabilities involved, a strategy they call “collaborative design.”³¹

Unlike U.S. manufacturers, which use a “one size fits all” approach, WWI seeks to ensure that the entire design and manufacturing process as well as the finished product empowers users. WWI criticizes the failure of the industry as a whole to do this, noting, “The key player that is most often overlooked is the wheelchair rider himself/herself.”³²

More out of humanitarian principles than market forces, WWI has adopted various strategies to incorporate people with disabilities at the center of its work. Most of the mechanics are wheelchair riders, who constantly rely on the feedback of local wheelchair riders in the intended area of use. For example, every time they develop a new model, a group of riders takes it out for a test ride, trying to detect and anticipate flaws in the design. In addition, persons in need of a Whirlwind are encouraged to fully explain all of their specific wheelchair needs. WWI recognizes that having an imperfect wheelchair-to-user match is much more serious than discomfort and can even result in death in less developed countries, as the improper wheelchair fit can cause the user to develop open pressure sores that infect easily without fast treatment.³³ Above all, the WWI team plays the role of cultural analysts, recognizing the significance of wheelchair designs that incorporate the local culture.

A recent example of WWI’s work abroad demonstrates the importance of addressing culture in wheelchair design. While working to create a new wheelchair for use in Uganda, a woman named Fatuma Achan explained a unique need that would not have been an issue in mainstream American culture. A WWI writer recalls this incident: “We asked what her unmet wheelchair needs were. She said she wanted to invent a chair that was close to the ground so she could cook. . . . Achan explained that she didn’t want to be able to cook just at her home, but that she wanted to be able to cook at her relatives’ houses, too. In much of the world, including Uganda, cooking is done at floor level.”³⁴ The group took her request seriously and designed a wheelchair that allows her to sit lower to the ground in her wheelchair, illustrating the power of the disabled voice at WWI.

The WWI model is worthy of attention, especially when looking to resolve the issue of technological abandonment in the U.S. As attested to by Ralf Hotchkiss’ firsthand experience as a wheelchair rider before founding WWI, U.S. manufacturers simply do not offer that kind of attention, despite the fact that our country has much more resources and funding available to do so.³⁵ WWI listens to and hears people with disabilities because, for the most part, they are people with disabilities themselves. Peter Pfaelzer and Marc Krizack, two of WWI’s earliest members, argue, “The reality is that very few non-disabled persons fully believe and understand what people with disabilities say, even about matters which a disabled person can be expected to know most.”³⁶ Because wheelchairs have such a huge impact on the bodies of

the users, it is common sense that they need to be highly involved in the design and manufacturing process, yet somehow U.S. manufacturers are missing this.

By recognizing culture and creating a space for people with disabilities to participate, WWI avoids the problem that led the wheelchair users I interviewed to decorate their chairs. Ruthee, Charles, Alexis, and Erin all felt that their wheelchairs were foreign to their bodies when they first received them, but how would they have felt if they had been involved in the process of designing and testing them? The WWI model ensures that, by the time the wheelchair rider is ready to use the chair, he or she does not feel it is a foreign object. Instead, the user is proud of the wheelchair, because it represents a huge accomplishment that showcases her or his individuality and diverse abilities, as both a rider and a partner in the manufacturing process. WWI provides a different means for personalizing wheelchairs, which, although less visible than wheelchairs with decorations, still achieves a similar result.

As I spoke with one of the first recipients of a Whirlwind from Nicaragua, I could see the pride she had in her wheelchair, as she boasted about how lucky she felt to receive it.³⁷ Hotchkiss witnesses this pride wherever he travels, but highlights the specific example of a teenager named Rafael Muturi in Kenya, whose only available wheelchair for eight years was used and of poor quality. Because it was such a poor match for his body, he developed pressure sores so severe that Hotchkiss believes, “Simply put, his chair was killing him.”³⁸ Rafael, still very sick from his infected sores, participated in a Whirlwind workshop to build his own wheelchair, which fit him much better than his earlier chair and allowed his pressure sores to finally heal. Rafael now takes great care of his wheelchair because he has a much closer relationship with it, having built it himself. In addition, this experience gave Rafael the confidence to finally persuade a headmaster to allow him to attend school. What he experienced is very common to WWI participants. Hotchkiss elaborates, “When wheelchairs are built by the very people who have been freed by them, pride ripples outward, spreading throughout the community.”³⁹ The pride that WWI helps spread in less developed countries could do a great deal of good for American wheelchair users as well.

Alexis’s experience at the Expo further illustrates the need to encourage WWI’s ideology in the U.S. wheelchair industry. Alexis entered the Expo with a list of specific features that she needed in her new wheelchair, but struggled to get the able-bodied retailers to recognize her requests because they were too busy trying to sell her the biggest, most expensive machines. Had she been working with WWI, her specific demands and needs would have been acknowledged, incorporated, and met in the cheapest way possible but without compromising quality. Reflecting on this makes me wonder whether Alexis or any of my other interviewees would have still felt the need to decorate their wheelchairs if they had had the opportunity to participate in the design and construction process.

While U.S. manufacturers continue to focus on making the most high-tech wheelchair, as exemplified by the iBOT, the worldwide love expressed by users for Whirlwind wheelchairs shows that U.S. designers may be going in the wrong direction. Whirlwind’s simple and practical designs also mean that users can easily maintain and repair their wheelchairs. This marks another contrast to the designs available in the U.S., where repairs to a wheelchair require highly specialized technical knowledge and skill; the cost and effort involved could well be a contributing factor in technological abandonment. In contrast, by creating a space for people with disabilities to work with wheelchairs, WWI helps users develop a highly personal relationship with the technology, which will help them in adapting to and maintaining a positive relationship with their new wheelchairs.

It is clear that, for the end user, WWI is “doing it right.” On an even bigger scale, WWI represents globalization at its best, for which there seem to be few positive examples in a global marketplace characterized by Export Processing Zones and child sweatshops. WWI, however, uses each trip abroad to set up a connection between the local economy and a global flow of ideas, so that wheelchair progress is not inhibited by patents and profit motive, as it seems to be in the U.S.

In order to make this happen, U.S. manufacturers must find a way to incorporate the drive for profit into meeting users' needs. While this subject could be another thesis in itself, I offer one potential solution: if the U.S. wheelchair industry were to seek to create more opportunity in their companies for people with disabilities, then perhaps more companies would begin seeing quality of life for people with disabilities as a goal with at least the same importance as the desire for profit. Because wheelchair users rely so heavily on these products, however, wheelchair designers should not wait until economic forces pressure them into taking such measures. Instead, they should see it as a moral obligation to take the advice of Ralf Hotchkiss and begin to "work with them."⁴⁰

Conclusion

With the ongoing war in Iraq and the aging of the Baby Boomers, the United States will shortly have its biggest disabled population ever, and many of these people will need to use wheelchairs. Anything that can be done to make the transition to using a wheelchair easier will play a significant role in their lives as well as in the lives of those already disabled. The four people I interviewed were able to accept the wheelchair by decorating and personalizing them. This strategy suggests that personalization is a significant method for resisting technological abandonment. But it is a defensive solution. The model of WWI, on the other hand, shows a more aggressive strategy in that it addresses the wheelchair users' comfort with the technology before it is even built. Both strategies offer possibilities that rehabilitation therapists have heretofore missed for lessening the possibility of technological abandonment. My research has continually confirmed what may seem an obvious solution: able-bodied people must recognize that people with disabilities know best what their bodies need in wheelchair design. In order to ensure that assistive technology is used to its fullest capacity, it must reflect the desires of the disabled community, through both its practicality and its aesthetical appeal. Finally, in order to more fully understand the relationship between wheelchairs and their riders, scholars and manufacturers alike must take into consideration the cultural context in which disability is defined. Wheelchairs are obviously about more than just mobility.

Notes

1. Richard Douglas, "Forward," in *Assistive Technology: A Resource for School, Work, and Community*, Karen Flippo, Katherine J. Inge, and J. Michael Barcus (Baltimore: Paul H. Brookes Publishing, 1995), ix.
2. Michael M. Behrmann, "Assistive Technology Training," in *Assistive Technology: A Resource for School, Work, and Community*, eds. Karen Flippo, Katherine J. Inge, and J. Michael Barcus (Baltimore: Paul H. Brookes Publishing, 1995), 215.
3. David B. Gray, Loius A. Quatrano, and Morton L. Lieberman, eds., *Designing and Using Assistive Technology: The Human Perspective* (London: Paulh Brookes, 1998), xix.
4. For more information on the Abilities Expo, see <http://www.abilitiesexpo.com/IAEBrandManager/v42/index.cvn>.
5. Abilities Expo: Southern California, The Anaheim Convention Center, June 12, 2004.
6. Abilities Expo: Northern California, Santa Clara Convention Center, November 14, 2004.
7. I do not intend to claim that I can offer any generalizations about the wider disabled community from these two Expos. However, I will offer substantive similarities between the two.
8. Denise L. Brown-Triolo, "Understanding the Person Behind the Technology," in *Assistive Technology: Matching Device and Consumer for Successful Rehabilitation*, ed. Marcia J. Scherer (Washington, D.C.: American Psychological Association, 2002), 32.
9. I would like to add that there are large issues here of the gender and age of wheelchair users, which I believe affect wheelchair users' interaction with sellers. However, I leave these large topics untouched for later research.
10. For information on the iBOT, see <http://www.independencenow.com/iBOT/index.html>.
11. Anaheim Abilities Expo, June 12, 2004.
12. Alexis Schey, interview by the author, 15 December 2004.
13. Helen Mialet, "Reading Hawking's Presence: An Interview with a Self-Effacing Man." *Critical Inquiry*, Volume 29, Number 4 (Summer 2003).
14. *Ibid.*, 585.
15. *Ibid.*, 577.
16. David Gartman. *Auto Opium: A Social History of American Automobile Design*, (NY: Routledge, 1994), 33.
17. *Ibid.*, 39.
18. *Ibid.*, 39.
19. *Ibid.*, 67.
20. *Ibid.*, 69.
21. *Ibid.*, 74.
22. Anne M. Ruben, "Woman's Mission Presidential," *Women are Wonderful*. <http://www.womenarewonderful.com/herald-article.html> (2001).
23. Rosemarie Garland Thomson, "Visual Rhetorics of Disability in Popular Photography," in *The New Disability History: American Perspectives*, eds. Paul K. Longmore and Lauri Umansky (NY: New York University Press, 2001), 346-347.
24. Gary Karp, "Adjusting to Disability: Getting From There to Here," Northern California Expo, 1:00 p.m., November 14, 2004.
25. Episode 203, *Pimp My Ride*, MTV, 2005.
26. Ralf Hotchkiss, interview by the author, 14 March 2005, emphasis added.
27. Ralf D. Hotchkiss, "Ground Swell on Wheels: Appropriate Technology Could Bring Cheap, Sturdy Wheelchairs to Twenty Million Disabled People," *The Sciences* (July/August 1993), 14.
28. *Ibid.*, 15.
29. Susan Baumrind, "Engineering a Better World for People with Disabilities." *Whirlwind Wheelchair International* 1 (October 2003), <http://whirlwindwheelchair.org/articles/archive/EngineeringaBetterWorld.pdf>.
30. Hotchkiss, "Reinventing the Wheelchair," *1998 Medical and Health Annual* (Chicago: Encyclopedia Britannica, Inc, 1997), 112.
31. Marc Krizack and Peter Pfaelzer, "Wheelchair Riders in Control: WWI's Model of Technology Transfer," *Whirlwind Wheelchair International* (8 March 2005), http://www.whirlwind.org/articles/current/article_c01/article_c01.html.
32. Marc Krizack, "It's Not About Wheelchairs," *Whirlwind Wheelchair International* (Fall 2002), 1.
33. Ralf Hotchkiss, "Reinventing the Wheelchair," 115.
34. Cathy Cade, "Wheelchair Cultures: Two Vignettes" *Whirlwind Women* (Fall 2002), 1.
35. Ralf Hotchkiss, interview by the author, 14 March 2005
36. Krizack and Pfaelzer, "Wheelchair Riders in Control."
37. Thelma Ayala, interview by author, 14 March 2005.

38. Hotchkiss, "Reinventing the Wheelchair," 115.
 39. Hotchkiss, "Reinventing the Wheelchair," 114.
 40. Ralf Hotchkiss, interview by the author, 14 March 2005.

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